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**A CASE STUDY OF BALANCE AND
INTEGRATION IN
WORTH-FOCUSED
RESEARCH THROUGH DESIGN**

JENNIFER CHRISHANTHIE GEORGE

A thesis submitted in partial fulfillment of
the requirements of the
University of Northumbria at Newcastle
for the award of
Doctor of Philosophy
Research undertaken in the
Faculty of Arts, Design and Social
Sciences
June 2016

Abstract

Understandings of, and objectives for, Interaction Design have been extended over the last few decades.

Firstly, a single user-centred focus for Interaction Design is no longer regarded as adequate where any single central focus for design is now questioned. Post-centric approaches such as Balanced, Integrated and Generous (BIG) Design propose to achieve a broadened worth-focused content scope for Interaction Design, where worth is the balance of increasing benefits over reducing costs and generosity of choice.

Secondly, there has been a broadened scope for disciplinary values in Human-Computer Interaction research, with the initial engineering and human science values of User-Centred Design and Human-Computer Interaction now complemented by the rapidly maturing creative field of Research through Design (RtD).

Thirdly, RtD as a form of creative reflective practice does not have a sequential process, but needs parallel activities that can achieve total iteration potential (i.e., no restrictions on iteration sequences). Structured reflective tools such as the Working to Choose Framework may reveal this potential.

An important opportunity remained that a complete challenging case study that integrated these domains (worth-focus) and tools (RtD, structured reflection) was carried out.

The case study addressed the challenging social issues associated with supporting care circles of individuals with disabilities. It is original in completely tracking the combination of RtD with worth-focused Interaction Design, supported by established user-centred practices.

The resulting research has made contributions through the tracking of the RtD process to: worth-focused design and evaluation resources; structured reflection; demonstration of innovative parallel balanced and integrated forms of iteration; and to future social innovation for disability support.

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P2 – ICF _2009
P3 – CAT Model_2010

<https://resourcesbyjennifergeorge.wordpress.com/>

Dedication

To my little Deborah Nyman who was part of this research during all of her two years and eight months. Thank you for your smile, the best in the world.

To Paul Gnanayutham who nurtured my interest in disability and introduced me to scones with strawberry jam and clotted cream, Viakal, the world of research, and my PhD supervisor. For being there when I started this PhD and then at the end of your life being a participant in my research. You knew I would finish it. Thank you for this gift.

To my Adonai, the “maker of each moment, father of my hope and freedom” (Avalon, 1997).

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Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this commentary has been approved. Approval has been sought and granted by the University Ethics Committee in March 2011 and November 2012.

I declare that the Word Count of this Thesis is 83,734 words.

Name: Jennifer George

Signature:

Chapter 1 - Introduction

The chosen research context for this research was improving the circumstances of those with disabilities, particularly in their choice and use of Assistive Technology (AT). This thesis develops, documents, and assesses the use of a novel Research through Design (RtD) approach that is post-centric and worth-focused, based on the Working to Choose (W2C) framework to support and structure reflection for this design research case study.

Research through Design (RtD) is a research approach to producing knowledge in design practice (Frayling, 1993/1994; Koskinen *et al.*, 2011; Zimmerman *et al.*, 2007). The design inquiry requires explicit research questions and the production of knowledge, for instance in the form of new methods, or a better understanding of the implications of a phenomenon. It provides a process whereby both problem and solution spaces can evolve together. In addition, RtD may also merge with research *into* design where existing literature on design is studied as part of the process and research *for* design that is carried out to identify reference material to design the artefact and to also produce resources for future research (Frayling, 1993/1994).

Cockton's research in the period 2004-2013 produced several methodological resources that supported *Worth-Focused Design* (WFD). WFD is a balanced integration of creative and human-centred design practices. The latter are specifically drawn from proposals for value-centred and worth-centred design methodologies (Cockton 2005, Cockton 2006). Worth relates value to costs, as a balance of value over costs, through which the design delivers sufficient value to outweigh costs of ownership and usage to the beneficiaries (Cockton, 2008a). Designing for worth is designing “for people to buy, learn, use or recommend an interactive product, ideally most or all of these” (Cockton, 2006, p.169). Cockton also proposed a *Working to Choose* (W2C) framework that supports the reflection within an RtD process (Cockton, 2013b, p.1).

Activities in a balanced design process are focused on one or more of the design arenas; *beneficiaries*, *evaluations*, *artefact* and *purpose* (Cockton, 2010). Rather than focusing on the artefact design arena throughout the process (Darke, 1979), a *post-*

centric process allows the design arena in focus to continuously shift. This enables *Total Iteration Potential* (TIP) through a form of *parallel methodology*, which allows for simultaneous multiple activities with a concurrent focus on multiple design arenas. This enables the iterative re-framing of the research problem until a preferred future state is proposed.

This chapter introduces the research reported in this thesis by:

- Stating the research problem with the related research question and how the question has been addressed in subsequent chapters;
- Giving the rationale for selecting a design case study in the context of disability;
- Briefly introducing the model of disability which will be used for this research;
- Introducing the approach taken for this research;
- Summarising the claims made in this thesis (and defended fully in Chapter 10) and highlighting the contributions to knowledge made by this thesis;
- Describing the structure of the remainder of this thesis.

1.1. Research Problem

Worth-Focused Design (WFD) methodologies have largely been proposals that have not been systematically tested in practice. Camara and her colleagues (2013) developed and assessed a worth-centred methodology for software development from an engineering design perspective. However, there has as yet been no full development and assessment of worth-focused approaches that are compatible with creative design practices. The research problem addressed in this thesis is the gap in understanding of how a worth-focus can be maintained throughout a broader and balanced RtD process.

The purpose of this PhD research is thus to address this research problem by:

1. Developing a new worth-focused design approach through a case study focused on an important social problem, disability;

2. Documenting and assessing the effectiveness of that approach in the context of a challenging design case study, and thus make a methodological contribution to the literature and practice on the emerging area of RtD;
3. Reflecting on the process using the *resource functions* vocabulary from the Working to Choose (W2C) framework.

1.2. Rationale for the Choice of a Challenging Design Case Study

Disability is a well-recognised social issue with associated legislation, guidelines and support systems. As of 2011, out of over 7 billion people worldwide, 15% live with a noticeable degree of impairment 27% of them being children between the ages of 0 and 14 (World Health Organization and World Bank, 2011).

According to the Office for Disability Issues (ODI, 2014) in the UK, the Family Resources Survey (2010/2011) reported there were over 11 million people with a limiting long term illness, impairment or disability with the most commonly-reported impairments affecting mobility, lifting or carrying. These 11 million individuals represent around 6% children, 16% working age adults and 45% over 60 years of age (ODI, 2013). Based on the mandatory primary and secondary education for children in the UK and opportunities it could offer for research, this PhD research started by focussing on supporting children. However, it became evident from the initial activities, described in Chapter 4 and 5, that the potential solution could equally be of use to adults, and therefore the subsequent activities included adults as well.

Assistive Technology (AT) is being increasingly used to assist, rehabilitate and support people with disabilities. Governments, governing bodies of web-related organisations, disability-oriented charities and researchers in both academia and industry have listed various criteria under which AT devices can be tested for those with limited manual dexterity. The World Wide Web Consortium (www.w3.org, 2008) also sets numerous accessibility guidelines such as Web Accessibility Initiative (WAI) and Web Content Accessibility Guidelines (WCAG). However, despite the existence of these criteria, according to a study by a team named *Matching Persons to Technology* (MATR, 2004), up to 75-80% of AT devices procured are being

abandoned. However, it is unclear if the problem is poor design of AT devices, poor choice of AT devices, or poor use of AT devices.

There are various reasons why AT devices may be so often discarded or unused. There is evidence both from MATR (2004) and activities reported in this research that a purely biomedical approach, which solely considers the medical condition of the individual to select AT, very often results in poor choices. This happens because even when the biological conditions of the individuals are similar, environment and personal factors can result in different demonstrable capabilities for individuals. In addition, technology may not be directly matched to the individual's specific need within the required environments. It may be that little or no training is provided to those who would be communicating with the individuals, or those who work with, or care for, the individual do not accept the technology. AT devices are also expensive compared to mainstream products, as they are not sold to a mass market. While AT devices are bought, for both adults and children, the choice and use may not lead to desired outcomes.

Dawe (2006) explored reasons why AT devices often ended up in a cupboard, rendering them useless. According to her research, the reasons for AT devices ending up unused included:

1. Inadequate understanding of disability;
2. Poor choice and use of AT;
3. Inadequate approach to assessment;
4. Insufficient legislation enforcing support devices and services to individuals with disability.

Dawe (2006) also showed that choice and usage of AT devices can also lead to conflict amongst members of the 'care circle', due in part to the time taken to familiarise themselves with the AT device. 'Care circle' in this context means those who care for a disabled individual and may include family members, medical practitioners, social workers, a disability assessment team, and educationalists; the term is used throughout the thesis.

Conflicts relating to AT devices during the decision making process could be reduced if members of the care circle were more involved in the choice and customisation of AT devices. Dawe concluded from her research that devices should have direct usefulness out-of-the-box without configuration or customisation, and that the value of the AT device should be evident within an acceptable period. Therefore configuration, updating and replacement are also expected to be easy and at a reasonable cost.

In order to improve the situation, it was important to first have a better understanding of disability. Thereafter, a theoretical basis for a systematic approach to analysing and enhancing AT and/or its use might be developed.

1.3. Model of Disability Used in this Thesis: International Classification of Functioning, Disability and Health (ICF)

There are various models of disability. The legal definition in the UK, where this research took place, is found in Section 6 of the Equality Act 2010, which describes a disabled person as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.

The International Classification of Functioning, Disability and Health (ICF) distinguishes between body functions, structures, activities, participations of individuals, and contextual environmental and personal factors (WHO, 2008), as shown in Figure 1.1.

The resulting network of concepts provides a basis for understanding and describing impairment that combines both medical and social approaches to disability. According to the ICF, the capability of an individual cannot be determined wholly by the diagnosis of their physical impairment. It is essential that contextual factors also be taken into account.

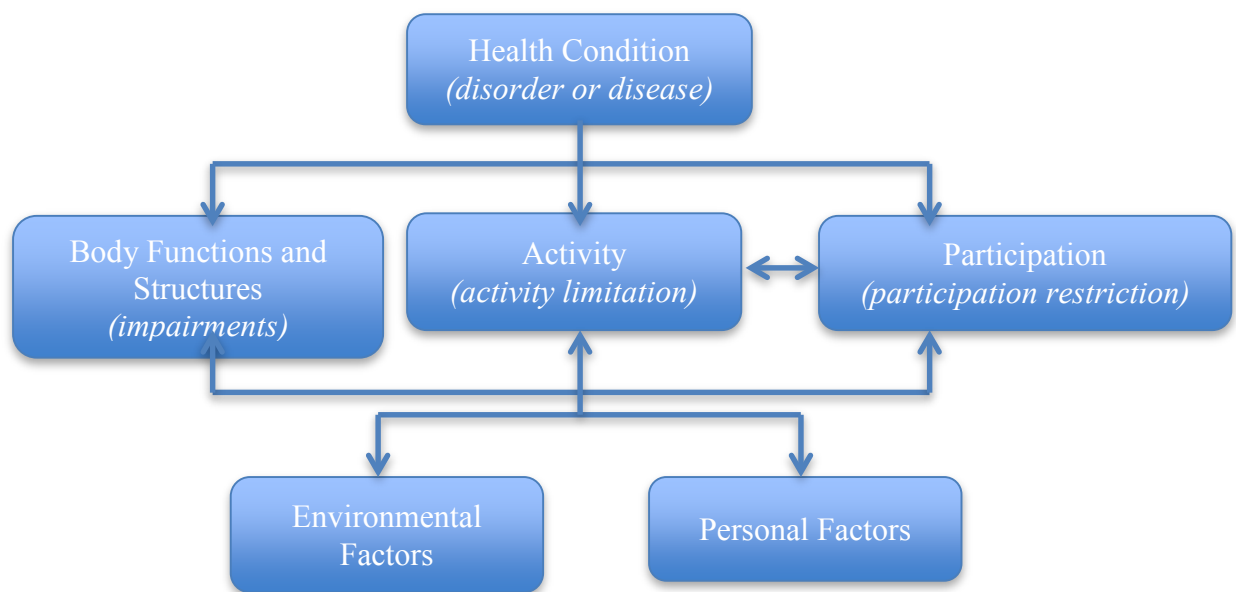


Figure 1.1 - ICF Classifications of Function and Disability

The need for a broader approach is also underlined by the British Standard BS8300 (2001), which addressed the design needs of the disabled population with respect to accessibility. Environmental factors are now considered for the elderly and disabled adults in the design of buildings, public services and products to encourage independent living. Nevertheless, there are no specific factors aimed specifically at disabled children, which represents a significant gap in current guidance.

Social services and private assessment centres, take an essentially biomedical approach when providing assessment and choosing AT, or providing personnel-based care and support for the family in managing the disability (details of which can be found in Chapter 3). Moreover, although children with special needs are being integrated into mainstream education from special needs schools, limited consideration is given to personal, environmental or social factors in the design of services and technology to cater to their rapidly changing needs. This does not, for the most part, respond to the broader guidance of the ICF model.

This gap between practice within different environments and international policies and guidance could be addressed by design of a novel system that supports design, choice and use of AT devices.

1.4. Research Question

This research is focused on individuals, interactive communication and lifestyle-related products. The aims are to develop a new worth-focused design research approach for the chosen case study, and to document and assess the effectiveness of this approach. Therefore, the overarching question is to understand,

What are the realities of Research through Design with a worth-focus, Total Iteration Potential and reflection guided by the Working to Choose framework?

In the case of this research, realities meant an honest recording of research process including anticipations, actual findings, challenges and abandoned resources.

The following subsidiary questions were used to investigate the response to this question to evaluate the approaches used, and the effectiveness of the approach developed throughout the thesis:

- What is the role of reflection in Research through Design?
- What is the nature of iteration in a parallel design methodology?
- What general conclusions on Research through Design (RtD), Worth Focused Design (WFD), Total Iteration Potential (TIP) and parallel methodology can be drawn from the practical application of these processes?
- How well can the Working to Choose (W2C) framework be used for the documentation and evaluation of the research approach and its findings?

1.5. Aims and Objectives

The aim of this research is to identify, innovate and effectively use Worth-Focused Design (WFD) activities (taking ICF fully into consideration within the case study) to improve the circumstances of individuals with disabilities that may be motor, sensory or cognitive related through a design intervention. The objectives are:

- to document and assess the effectiveness of the chosen approach in the context of a challenging design case study;
- make a methodological contribution to the literature and practice on the emerging area of RtD and

- improve the circumstances of individuals with disabilities.

1.6. Research Approach

Whether it be designing an AT device or a system that supports the design of AT or a care service for individuals with disabilities, design has the potential to meet the needs of the disabled. The Design Council (2013) refers to Design as the link between creativity and innovation and a tool that meets social needs. Prior to that, Latour (1991) rationalised how technology and other non-human factors could be woven into human factors to provide durable and sustainable solutions for social issues and claimed that “technology is society made durable”. This research connects the design of technology with a social setting and aims to structure reflection across an RtD process using the W2C framework of concepts. This is an approach that enables a balance of worth by regularly considering *beneficiaries*, *evaluations*, *artefacts* and *purpose*.

Potential design research can be approached through combination of separate research paradigms:

1. Primary research, where the researcher carries out activities first hand, is as important as secondary research that reviews data that is already available;
 2. Substantive knowledge can be obtained via experiments in primary research. However, as it is not possible to control variables or recruit large enough samples for research across disabilities, this approach is not suitable. Substantive knowledge can also be obtained by naturalistic inquiry, but that does not identify causation or provide solutions that do not already exist.
 3. Action Research with Reflective Practice can enable practical knowledge where the researcher continuously *looks* to gather information; *thinks* to analyse and reflects on the information and *acts* in planning and implementing their intervention.
- 3.1. Rehabilitation Engineering is a form of Action Research and primarily has a biomedical approach that attempts to rehabilitate individuals with disability. However, the focus of this research is to look beyond mere

biomedical condition of the individual and support the environmental and social factors to improve the support provided. Therefore, this rehabilitative approach is not suited to this study;

3.2. Action Research in the form of RtD allows sufficient flexibility to include other research paradigms and is led by design activities. As a research paradigm/approach, it focuses on producing knowledge rather than a profitable or commercial solution and was chosen as the appropriate paradigm for this research.

A methodology to carry out the chosen paradigm was developed in the course of this thesis building on the following three considerations:

1. The *choices* or *arenas* involved in designing can span *beneficiaries*, *evaluation*, *artefact* and *purpose*. Rather than focussing on a single design arena, *post-centric* design potentially allows multiple foci to shift during the design process. There is no single predetermined centre before design begins, and nothing remains fixed as the ‘centre’ during design.
2. A methodology could be sequential or parallel. When design activities follow one after another, it is sequential. If activities were conducted concurrently, it would be parallel. Sequential approaches were not sufficient as the problem and solution had to be continuously reframed. A parallel methodology was needed, with flexibility in focusing on one *design arena* in relation to the others, which supports *Total Iteration Potential* (TIP).
3. Worth was chosen as a suitable focus for design purpose, rather than a single focus leading the entire process.

Several research activities were considered as potential methods to implement the chosen methodology. These were considered in the light of their potential functions and contribution to the research. The *resource functions* vocabulary from the W2C framework was used to identify possible, and upon reflection, actual functions.

1.7. Contribution Statement

This PhD primarily makes contributions to research on Research through Design (RtD) in practice. There are also secondary contributions to Worth-Focused Design

(WFD) and parallel methodologies with Total Iteration Potential (TIP) in practice. In addition, the research also provides new resources for future research and practice for disability care. The research records twenty-three activities that were planned, executed and used at various points in the research, sometimes sequentially but largely simultaneously, making the research methodology parallel.

When the choice is made that the *purpose* of design will be expressed as intended worth, this can provide the focus for co-ordination of other types of design arenas, i.e. arenas related to *beneficiaries*, *evaluations* and *artefacts*. Worth-Focused Design has the goal of co-ordinating all design activities via design purpose (when that is framed as the achievement of worth). However an immediate focus on worth as design *purpose* may not be possible. Initial design may have to work to establish design *purpose* via individual activities that may themselves be primarily focused on possible designs (*artefacts*) or possible *beneficiaries*. Later, design becomes increasingly focused on demonstrating that a worthwhile system can be developed. Such a system would be a response to the values of chosen *beneficiaries*, meeting relevant needs and wants of identified stakeholders at acceptable cost, and thus deliver extensive worth. Throughout this process, design arenas related to *beneficiaries*, *evaluations*, *artefacts* and *purpose* are continuously iterated and coordinated, demonstrating TIP.

Thus, the key contributions of this research together with their claims are as follows.

1. Research through Design requires Reflection *on* Action, which can be made more productive and effective through conceptual structures based on the structure and content of design work and supported by appropriate tracking.
2. Frayling's Modes for Research in Art and Design can combine in several ways.
3. Design generators are complex, dynamic and short lived as revealed by appropriate tracking.
4. Total Iteration Potential is more complex than in the Value-Centred Design Framework (Cockton, 2005) and requires parallelism, as revealed by appropriate tracking.
5. New Worth-Focused approaches have been developed and combined effectively in a challenging case study, as evidenced by appropriate tracking.

6. The final design research artefact My Care Circle Version 2 is a well-developed basis for future development through a sponsored service design.

1.8. Research Challenges

The specific challenges encountered in this research were as follows:

- This research was conducted part-time while the researcher was in demanding full-time jobs, so at times it was necessary to take breaks from the research. The part-time PhD took almost seven years to complete, over which period the rationale for the research and case study was expected to change. However, periodic activities, showed that the demand for improved choice and use of AT remained the same;
- The chosen case study was not in a mainstream setting and therefore identifying initial data gathering environments was a challenge;
- While sufficient participants were identified to provide the exploratory study, once the potential care circle membership was identified, recruiting entire care circles to include disabled individuals proved to be difficult;
- It was not possible to get care circle members who were identified to commit for the entire duration of the research;
- As anticipated, digital technology based solutions and demand changed over the duration of the research. New systems and technologies such as Google + arrived and other technologies such as the free version of Ning (ning.com, 2008) left the market;
- The methodological context of this research continuously evolved over the course of this research. As shown in Table 1.1, when this PhD started in 2008, it was based on Cockton's work between 2004 to 2009 focused on value-centred and worth worth-centered design. His work further evolved to a worth-focused approach from 2011 to 2013 in combination with Research through Design (RtD). His Working to Choose (W2C) framework has evolved to integrate concepts that were introduced and revised over several years (2007-2015).

Table 1.1 -Research Approach Progress

Research	Period	Concepts
Cockton (2004), Cockton (2005), Cockton (2006),	2004-2005	Value-Centred
Cockton (2007), Cockton (2008a), Cockton (2008b), Cockton (2008c), Cockton (2009)	2006-2009	Worth-Centred; Worth maps.
Cockton (2009a), Cockton (2010a), Cockton (2010b)	2009-2010	Worth-focussed, meta-principles, abstract design situations,
Cockton (2011), Koskinen, <i>et al.</i> , (2011), Cockton (2012a), Cockton (2012b), Cockton (2013a)	2011-2014	Worth-focused, Research through Design with W2C Framework.

- It was a challenge to remain aligned with a continuously changing methodological context keep shifting with the moving target of Cockton (2009) over this period. One example was meta-principles and having to replace them entirely with resource functions (Cockton, 2013a).

This provided an opportunity for this research to explore how Research through Design (RtD) would integrate with Worth-Focused Design (WFD) and the Working to Choose (W2C) framework.

1.9. Thesis Structure

The remainder of this thesis is structured as follows:

Chapter 2 - Research Paradigms, Methodologies and Methods

This would be Chapter 3 in a usual thesis. As the main contribution of this research is methodological, the literature review is focused on research approaches. This chapter explores a range of potential paradigms, methodologies and methods, and selects an appropriate approach for this research. The chosen paradigm, RtD, combined with WFD, TIP and parallel methodology, results in planned open phases with reflective steps marking ends to phases. This provided an opportunity for making decisions on the methods used in the subsequent phases at each reflective point. The chapter ends with a plan for the first iteration of the research.

Chapter 3 - Contextual Review

This chapter presents the review of literature within the chosen case study. This review of literature is of the chosen case study and is secondary to the literature reviewed in Chapter 2 which was the core subject of research. This chapter starts by thoroughly exploring the ICF model and other disability models in order to get a better understanding of various perspectives of disability. This is followed by an exploration of existing disability assessment methods, AT devices that meet biomedical needs and existing legislation. The chapter finishes by discussing the potential research approach to this design situation.

Chapter 4 - Iteration 1: Decision Support System as a Possible Artefact

This chapter starts with an activity in support of a possible decision support system based on preliminary assumptions and their initial investigation. Further activities are conducted to evaluate the viability of such a system and identify *purpose* from intended *beneficiaries*. Each activity provides, refines or challenges options related to intended beneficiaries of the study, the purpose of the design solution, and suitable design solutions. A worth table is created to connect design arenas.

Chapter 5 – Iteration 2: A Social Support System as a Possible Artefact

Chapter 5 explores possible existing solutions that may better meet the needs established at the end of Chapter 4. The desirability of this potential *artefact* is evaluated by further activities. Design purpose is also extended. An existing disability model is used to understand the requirements for the alternative design solution. A worth table is created to connect design arenas.

Chapter 6 – Iteration 3: Confirming Requirements of a Probable Artefact

Based on activities from Chapters 4 and 5, worth sketches and a novel design representation using worth tables and worth shift tables are created to identify assumptions that require confirmation and gaps in information. Questionnaires are designed to obtain this information, with a pilot study to test the questionnaire. Following revisions, a survey is carried out. Further worth sketches are created in each stage of revision. Chapter 6 reports on these design activities.

Chapter 7 – Iteration 4: Design and Development of Chosen Artefact Version I

This chapter starts with the design of personas and the requirement specifications for the design artefact. It goes on to report on the design and development of a social support system.

Chapter 8 – Iteration 5: Evaluation of Artefact Version I and Development of Artefact Version II

Chapter 8 reports on persona-based, expert-based, and user-based evaluations. A further activity is conducted to strengthen the validity of the research. This Chapter ends with the redesign of the artefact.

Chapter 9 – Iteration 6: Further Evaluation and Development of Artefact Version II

This chapter starts with the co-design of content for the website to start interaction and evaluation. This is followed by continuous feedback and redesign that continues to shape the artefact. The chapter ends with the revision of worth tables and worth sketch.

Chapter 10 – Analysis of Research Approach and Case Study

Chapter 10 conducts a meta-reflection, and analyses the findings with reference to the identified research approach in Chapter 2 and contextual review in Chapter 3.

Chapter 11 – Summary and Conclusions

Chapter 10 summarises the chapters, revisits the research question, aims and objectives, presents the claims and confirms the original contributions to knowledge. It also suggests future work that can be carried out from this research.

A detailed guide to this thesis ('Guide to Thesis'), focussing on the iterations is provided to help the reader follow through the different components of the reflection and structure of Chapters 4-9. Please refer to this guide to refer to as needed when reading through the thesis.

1.10. Ethical Approval

Ethical approval was obtained in two stages of the research. The initial activities were conducted with family members and professionals involved in the decision making process for individuals with disabilities. This first ethical approval covered activities recorded in Chapters 4, 5 and 6 and data protection (Appendix C1 – Ethical Approvals).

The second approval was obtained for populating the platform with information with a GP from the NHS, evaluating the platform with professionals and family members of disabled individuals and data protection.

Chapter 2 - Research Paradigms, Methodologies and Methods

The second chapter of most theses would be a literature review and the third chapter would concern research approaches. As the main focus of this thesis is design research approaches, this literature review chapter explores research paradigms (which are broad approaches), methodologies (common ways of working within a paradigm), and individual approaches (methods) that could be part of these structures.

2.1. Research Paradigms and their Suitability for this Research

A paradigm, in its simplest form, is a way of looking at things, or in the case of this research, an established way of approaching a situation. The term paradigm in scientific research was popularised by Kuhn (1996, p.10) and defined as: “universally recognized scientific achievements that, for a time, provide model problems and solutions for a community of practitioners”. (Methodologies are part of the model solutions, and address model problems).

In the case of this research, there are different ways of addressing the problem where the majority of Assistive Technology (AT) devices used by disabled individuals often end up unused due to various reasons. If this problem were considered purely based on the biomedical understanding of disability, bodily impairments would be *the* design problem. However, in the case of this research, the *why* (purpose), *what* (artefact) was being designed, *who* (beneficiaries) it was being designed for, and whether the design solution delivers intended benefits (evaluation) were yet to be established. Hence it became necessary to move beyond a biomedical understanding of disability to a broader understanding of disability (Chapter 3). A range of potential approaches was explored for this research and grouped as paradigms based on similarities, which are presented in this section.

2.1.1. Primary vs. Secondary Research

The initial focus in this research was to increase the understanding of the design research case study of improving the choice and use of AT devices and thereby improving the circumstances of disabled individuals.

Secondary (or desk) research can, if a body of research is already in existence, provide a good understanding of a design problem and point to options in understanding who the beneficiaries of the solution are, what the artefact may be, what purpose this would serve and if the solution would be demonstrably beneficial to the beneficiaries. Secondary research identifies data or information that already exists in published sources such as books, journals, conference proceedings, which may already be known by those interested.

When this secondary research has provided the available information, further primary research activities may be required to collect data that has not been acquired previously from subjects or experiments (Rugg & Petre, 2007). Primary research may also lead the research to further secondary research. Primary research alone may be insufficient.

Research, both primary and secondary, has already been conducted on disability, AT devices, approaches to disability, and also potential approaches to assembling a design solution. Therefore, desk research was of great relevance, and so was used for this research (see Chapters 2, 3 and 5 - Activity 5). But while desk research can provide ideas for potential solutions, it is not capable of providing a design solution that does not exist, or of addressing any novel problems or newly identified purposes that have not been addressed previously. Given that the chosen case study was not one that has existing design solutions, neither primary nor secondary research were sufficient on their own. Desk research was necessary to understand the context better and explore possibilities for design solution, but primary research was required to obtain further knowledge on the context, design and evaluate solutions.

2.1.2. Substantive vs. Practical Knowledge

Having established the need for both primary and secondary research, the next step was to identify the type of knowledge that needed to be acquired. On a theoretical

level there are two well established categories of knowledge: *knowing-how* and *knowing that*. *Knowing-how* is also known as *knowledge-how* or *practical knowledge*. *Knowing- that* is also known as *knowledge-that*, *explicit knowledge* or *substantive knowledge*.

Ryle (1946), argued that “knowledge-how cannot be defined in terms of knowledge-that and further, that knowledge-how is a concept logically prior to the concept of knowledge-that”. He explained that in order to intelligently carry out an activity (*knowledge-how*), you needed to know information about it (*knowledge-that*). He argues that the *how* is dependent upon practice of *that* (theory or rules). Fantl (2008, p.465) builds on Ryle’s approach to explain the *knowing-that* that are required for different levels of *knowing-how* as follows.

Where S is a noun and ϕ is a verb, S knows how to ϕ only if:

1. it is possible that S ϕ .
2. were S to try to ϕ , S would ϕ .
3. were S to try to ϕ in a suitable context, S would ϕ .
4. S is able/has the ability to ϕ particularly well.
5. S knows that w is a way to ϕ .
6. S knows that w is a way for her to ϕ .
7. S knows why w is a way to ϕ .

Points 1-3 refer to the levels of knowing-how making competence and ability key. Point 3 is the most definite level of knowing-how and points 5-7 show that knowing-that is not sufficient on its own.

In this research that meant substantive knowledge was needed to understand how: disability assessments are carried out; assistive technology is chosen and usage is continued. Practical knowledge (*knowing-how*) in respect of these topics was less important as the researcher would not be carrying out these assessments or choosing AT devices. But both substantive and practical knowledge were needed in respect of the research approaches that underpinned the Research through Design (RtD) process.

Having established that substantive knowledge was key to understanding the chosen context, it was necessary to consider how this knowledge might be gathered. Substantive knowledge is based on existing facts that are proven to an acceptable degree of confidence. There are a number of ways of gathering or generating substantive knowledge. Secondary or desk research, as seen in Section 2.1.1 can reveal existing substantive knowledge but was not in itself sufficient for this research. One alternative would be to use experiments, which produce knowledge through observation of the effects produced when some aspects of the experimental environment are manipulated (provided the experiments can be repeated, measured and results replicated by others). Experimental data can then be used to address research questions in an objective way (Field & Hole, 2003, p.3) to produce substantive knowledge.

In the case of a research situation such as this, particularly involving biomedical conditions, where demographics, environments, associated activities and personal factors are all relevant, it is not possible to manipulate a few variables while holding all potential confounds constant as required for controlled experiments. No two individuals will have the same extent of disability, and no two individuals will have similar social and environmental conditions. Even in rare cases where siblings have identical disabilities, even though they would have environments in common, the personal factors would be different thereby making some factors change. It is also not possible to recruit a large enough stratified sample to allow the use of inferential statistics to establish the relative influence of all contextual variables. Therefore, an experimental approach is not suitable for this design research setting.

As the primary focus of this research was on identifying a design solution to a problem that was not fully comprehended yet, substantive knowledge could not be the predominant basis for this research. Having stated this, whilst it was not possible to take an experimental approach to the potential beneficiaries in the chosen case study, it is possible to take experimental approaches to features of a design that could be developed by trial and error.

In conducting experiments, the validity of data is assured in several ways. While an experimental approach was not suited to this research situation, a variety of other

approaches and methods were used during the research and design process. Therefore, it was important to have an understanding of the validity of each of these methods. Gray and Salzman (1998) categorise validity into the following five types.

The first validity issue is *Cause Effect* and refers to whether the study was designed and conducted well. Both statistical and internal validity helps establish any relationship between independent and dependent variables.

- (1) *Statistical Conclusion Validity* establishes if the independent variable is connected to the dependent variable. For example, the conclusion of an experiment may be misleading due to excessive variance by low statistical power (i.e. fewer samples) where the difference may not be noticed, random heterogeneity of participants where the noticed differences may not be accurate and making too many comparisons.
- (2) *Internal Validity* refers to the instrumentation of the study and is whether it can be concluded that the independent variable caused the observed change in the dependent variable, or another confounding variable was responsible.

Generality issues relate to whether the effects can be “generalised to alternative cause and effect as well as different types of persons, settings and times”.

(3) Construct Validity

3.1. *Causal Construct Validity* concerns whether the experiment is manipulating what it claims. This refers to the potential difference between the experiment and the perceived experiment. i.e. an actual independent variable does not correspond to the perceived cause.

3.2. Another type of construct validity *Effect Construct Validity* and refers to whether the experiment is measuring what it claims to be measuring, i.e. the dependant variable.

(4) *External Validity* refers to both generalisation of experimental results to the general population and across subpopulations specific to particular target persons, settings, and times.

(5) *Conclusion Validity* is lost where the study draws incorrect conclusions from results.

Section 2.1.4 explains how validity is addressed in the activities carried out in this research.

Naturalistic Inquiry is another form of research that can be used to gain substantive knowledge. It is a “research that focuses on how people behave when absorbed in genuine life experiences in natural settings” (Frey *et al.*, 1999, p.257). There are four common types of naturalistic inquiry: ethnography, ethnomethodology, critical ethnography and autoethnography.

Ethnography is a systematic study of a culture in a naturalistic environment. The ethnomethodological approach is a specific approach to ethnography developed by Garfinkel (1967) and is based on the availability of common sense knowledge of society. The purpose of this methodology is to discover the expectancies and codes that lie behind everyday behaviour. This could either be for pure research used for everyday life, or applied research dealing with communication (Berger, 2000).

Naturalistic Inquiry, more specifically but not exclusively ethnography, is relevant and was used for this research, as the behaviour of people in natural settings, which are to some extent dependent on cultural factors, is highly relevant to the success or failure of AT. However, this approach has limitations. Existing solutions for dealing with the impact of disability may have been adopted by a particular individual or group and can readily be identified through ethnographic study, but these will not necessarily be the best or only solutions. Naturalistic Inquiry also does not identify causation, as it does not allow for the control of variables. Moreover, Naturalistic Inquiry was not sufficient in itself, as it does not directly provide or lead to a design intervention. Therefore, other approaches were needed to go beyond current practices or technology.

Substantive knowledge is required to start on the RtD process (obtained in this chapter). Practical knowledge of research approach is necessary to carry out the research i.e, Research through Design. Research on the chosen case study could start with substantive knowledge based on secondary research, with naturalistic inquiry, primary or secondary research activities to complete the knowledge required. While practical knowledge may be beneficial within the chosen case study it is not necessary.

To establish what substantive knowledge is required next, reflection points are necessary to look back and plan forward. This can occur within a broad Action Research cycle as discussed in Section 2.1.3.

2.1.3. Action Research and Reflection

Action Research is an approach to practical problems using both primary and secondary research and substantive and practical knowledge. Reflection is a form of response to the researcher's experience, where the experience can refer to the subject being studied and the practice of research. Historically, Action Research practice combines observing people with behavioural interventions and the researcher reflecting on his or her own practice and then intervening. It can be applied to any field of practice such as education, project management, therapeutic practices such as Speech Therapy and counselling where actions are planned, implemented and reviewed continuously in a cycle.

2.1.3.1. Models of Action Research

What makes Action Research unique is that it improves the subject of research, in this case understanding the assessment, choice and use of AT by disabled individuals and generates knowledge at the same time (Kock, 2013).

For a design intervention to be proposed for the chosen design situation, suitable opportunities should be identified and further substantive and practical knowledge needs to be gained. This could be in multiple cycles, and the process may have to be repeated. This made Action Research approach appropriate for this research, and therefore a few relevant Action Research approaches are discussed in this section.

Action Research studies normally include multiple cycles of intervention. The cycle includes identifying the problem, planning the intervention, developing and applying of a solution and evaluating by the research and client. This is followed by reflecting on the learning and formulation of new knowledge by the researcher where reflection refers to reviewing an experience, learning from it and taking action.

Action Research is also a common model in Rehabilitation Engineering within the disability domain. This refers to the design, development, application and evaluation

of rehabilitative or assistive devices to support individuals with temporary and long term conditions in independent living. The goal of rehabilitation engineering is to support individuals' self-determination according to the ICF's model described in Chapter 3 (Cooper *et al.*, 2007). Rehabilitation Engineering research centres such as RESmaG (<http://resmag.org.uk/>) attempt to address the requirements of disability and inclusion legislation by exploring solutions for various social settings such as specialised wheelchairs, walking aids and some interactive devices.

As a design approach to the research problem in this study, rehabilitation engineering seems relevant, and it is one of the major current approaches taken to supporting disability. However, based on the ICF approach to disability that has been adopted for this research, (further explained in Section 3.4), rehabilitation engineering is a biomedical approach and does not approach the chosen case study holistically and is therefore not appropriate.

A widely referenced Action Research cycle has been that of Susman and Evered (1978) and has the following steps (Figure 2.1):

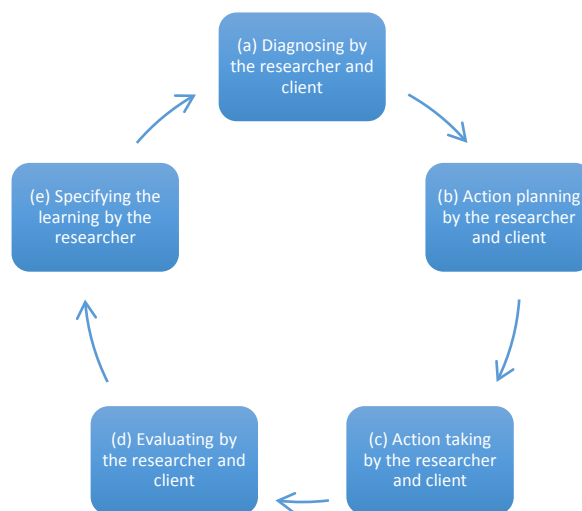


Figure 2.1 - Susman and Evered's (1978) Action Research Cycle

However these steps are interpreted and applied in different forms based on the context of application. In this section, Action Research is reviewed within three contexts.

The first one originates from educational practitioners Carr and Kemmis (1986, p.162), who Action Research as “... *simply a form of self-reflective enquiry*

undertaken by participants in social situations in order to improve the rationality and justice of their own practices, their understanding of these practices, and the situations in which the practices are carried out”. While, such self-reflection does provide a higher level of substantive knowledge (Fantl, 2008, p.466) this would be insufficient for a design situation that has several stakeholders.

The second form of Action Research is “the systematic collection of information that is *designed to bring about social change*” (Bogdan and Biklen 1992, p.223). This latter approach refers to Action Research as defined by Lewin (1948) who introduced the term ‘Action Research’ as research that could take place within any community of social practice and practiced for social management or social engineering. This definition assumes that substantive knowledge always leads to practical knowledge. Based on Fantl’s position (levels 4-7 of knowing-that required for knowing-how), this may not always be the case. Therefore this form of Action Research is not sufficiently open to further practical knowledge that may be required to allow the action to be implemented.

The third and more recent Action Research approach within the Human Computer Interaction (HCI) domain is defined as the three following phases (Stringer 1999, pp.18 and 43-44, 160):

- “Look - building a picture and gathering information. When evaluating we define and describe the problem to be investigated and the context in which it is set. We also describe what all the participants (educators, group members, managers etc.) have been doing.
- Think – interpreting and explaining by reflection. When evaluating we analyse and interpret the situation. We reflect on what participants have been doing. We look at areas of success and any deficiencies, issues or problems.
- Act – resolving issues and problems. In evaluation we judge the worth, effectiveness, appropriateness, and outcomes of those activities. We act to formulate solutions to any problems”.

This approach can be summarised as *look* to gather information; *think* to analyse and reflect on the information and *act* in planning and implementing of the reaction. This would loop to the next iterations to gather information and follow on. This definition

does not assume any type of knowledge within the three steps and is continuously open and is therefore most relevant this research. This also maps against Figure 2.1 by Susman and Evered (1978) with (a) Look (b) Think, (c) Act, (d) Evaluate and (e) specifying the learner requirements. However, while this form of Action Research is widely used in practice-based design research, it has no documented evidence for being used within this context of HCI.

On the contrary, in the chosen design context, it is not yet possible to say if this model of Action Research and reflection cycle can be followed in this order as the need for substantive and practical knowledge needs to be driven by the reflection. While reflections can be part of Action Research, they are largely based on tacit personal resources. While this can be effective, the reflection needs to be based on evaluation and feedback from stakeholders at appropriate points, and otherwise based on explicit critical structures. Therefore, this third form of Action Research on its own will not be sufficient for this research and a more appropriate form of Action Research is required.

2.1.3.2. Research through Design (RtD)

In the creative research design domain, a form of Action Research that is growing in popularity is Research through Design (RtD). However, RtD is rarely communicated as being a form of Action Research. Instead, RtD is “a research approach that follows a design process of making things (design inquiry) where the goal is the production of knowledge, not a commercially successful product” (Zimmerman & Forlizzi, 2011, p.15). Design inquiry would involve having explicit but dynamic research questions that are responded to through a documented process. This approach enables design researchers to identify significant opportunities for innovation; provides them with motivations and inspiration for design solutions; and allows them to identify important gaps in behavioural theory and models, and to discover ways of filling them (Zimmerman *et al.*, 2007). It is also an approach that acknowledges the explorative nature of design activity and is a valid approach to answering research questions.

This “production of knowledge” referred to in the definition could be in the form of methods, implications, “how to design” or successfully fielded systems. Zimmerman *et al.*, (2010, p.313) also explain that RtD practitioners “iteratively design(ing)

artifacts as a creative way of investigating what a potential future might be”. This is in practice done by integrating creative design engineering, behavioral science and anthropological approaches and does not have to follow a sequential process.

Research through (design) practice has been framed in several ways. Applied and fine arts have developed practice-based approaches over the last two decades. RtD has developed separately in different disciplines. User-Centred Design (UCD) has always had elements of practice-led research, but design-led research has recently become more prominent (Zimmerman *et al.*, 2007, Koskinen *et al.*, 2011) within the discipline of HCI (Fallman, 2003).

A significant source for RtD is Frayling (1994), who presented research (small r) *into* design as knowledge examined and produced from the design work that is being carried out by way of routine research. The analysis of this corpus of knowledge may lead to research *for* design.

Frayling (1994) distinguishes between Research and research *for* design. From his discussion with regard to big R and small r, the following is the position this research takes. Research (big R) *for* design is a framework that improves designers’ practice and knowledge by making them aware of new methods, tools, context, users, technology, new spaces and the ability to analyse existing designs to understand patterns and principles (similar to Zimmerman *et al.*, 2010, p.313) which is the frascati definition of Research *for* design. Frayling presented research (small r) *for* design as the activities carried out to respond to the design inquiry. This may include both primary and secondary research where these approaches had to be considered to identify what they would be used for.

In summary, Frayling (1994) proposed three types of research that are conducted in the field of art and design that can be applied to HCI. This research takes the following position:

1. Research *into* art and design, that requires conducting predominantly historical research, visual analysis or research into variety of theoretical perspectives on existing information on art;
2. Research *through* art and design, where:

- a. Materials research that can be conducted by an experimental approach;
 - b. Development work that can be conducted by carrying out a design process and communicating the results;
 - c. Action research where a detailed reflection based on the context is provided for the communication of the results.
3. Research (small r) *for* art and design, which is gathering of reference material, both literary and visual to produce a piece of art, where the expressive outcome is an artefact. Research (big R) *for* design, which is the creation of new resources that can be reused in future research.

Yee (2009) states that while Frayling (1994) covers all design possibilities, these categories are not mutually exclusive and they can and must combine as research *into*, *through* and *for* design together. This thesis demonstrated how the three categories interact throughout the research.

It is interesting to note that, in hindsight, some engineering research practices have similarities with Frayling's outline of RtD. For example, Classic Engineering Design Research (Pahl & Beitz, 1984), Sutherland (1963)'s Sketchpad, Xerox Star that had aspects of UCD, making RtD a design research practice older than it has been recognised.

Koskinen *et al.*, (2011) in their book refer to RtD as a Constructive Design Research that is practiced in labs, in the field and in showrooms, and imagines and builds new things instead of simply describing them. This includes making several versions of things and iteratively evaluating them with multiple stakeholders and re-framing the problem to a proposed preferred state thus involves both substantive and practical knowledge. This research conducts RtD in the field setting and both problem and solution spaces are continuously re-framed. However, except for highlighting that reflection is limited in the context of RtD, this book does not provide any structure or guidance for reflection.

Koskinen and his team's (2011, p.5) book also challenges, Frayling (1994)'s definition of RtD stating that any RtD practice would need theories that guide the practice. However, Gaver (2012, p.940) and Gaver and Bowers (2012) argued that the outcome of design practices, such as annotated artefacts can contribute to theory

development. Koskinen and his team take a position to Ryle (1964) where substantive knowledge leads to practical knowledge and Gaver opens the possibility for Fantl (2008)'s variations of practical knowledge and further extend it to practical knowledge leading to substantive knowledge. This thesis is fluid in documenting both theory and artefact development retrospectively recognised on reflection the type of knowledge that led the other in the research process.

A significant form of reflection is of Schön's (1983), where double-loop learning that starts with an existing mental map of the social setting. Single-loop learning includes goals, values, frameworks and, to a significant extent, strategies that are taken for granted where the reflection itself is on making the strategy more effective. Double-loop learning also questions and evaluates the role of learning system that underpins the process, where learning system refers to an inductive process where individuals and organisations are capable of bringing about their own continuous transformation.

The notions of reflecting *in* and *on* action are also closely linked to this. Reflection *in* action refers to thinking on experiences, circumstances and theories that define understanding while it is taking place, while reflecting *on* refers to looking back and rationalising this, which is the same as research *into* design.

Gaver and Bowers (2012) presented a reflective framework for annotations within RtD practice. This framework has seven features: constitution, relationships, communication, perspective, mutual informing, shaping and materiality. While this framework may have had a potential in this research, it was published in 2012 and this research was already committed to a different reflective framework as described in Section 2.2.2.4.

This made, RtD within a field setting an approach that was sufficiently open to respond to the chosen research situation but requiring systematic reflection.

The RtD process started with a design concept (recorded as Activity 0 in Chapter 4) that was followed by a rigorous RtD approach which continuously reframed the research problem as identified in Chapter 3 and documented the approach in detail, as recorded in the activities and chapters that follow.

While there are several structures for Action Research, there are no structures provided for their reflective component within existing models of Action Research. Therefore it was necessary to identify different reflective frameworks and create one that would fit into the RtD framework for this research. The reflective frameworks used in this research are explained in Section 2.2.2.4.

2.1.4. Validity of Knowledge from Research through Design

Five types of validity *Statistical Conclusion Validity*, *Internal Validity*, *Construct Validity*, *External Validity*, *Conclusion Validity* were presented in relation to experimental studies (Section 2.1.2). As with experiments, they related to manipulating independent variables and measuring impact, which is not relevant to an RtD process.

However, since RtD is a type of Action Research, the validity of the findings needed to be assured in alternative ways. This section looks at validity of substantive knowledge elicited in the context of RtD.

In the process of responding to the research questions, the RtD process itself was structured to address *Conclusion Validity*. Attention was paid to detail of each activity, which made this research more challenging while delaying results (explained in Chapter 10).

Internal and *External Validity* were maintained by continuous points of reflection that were required when making a design inquiry. Reframing of the problem took place by making several versions of things and iteratively evaluating them. As a study that focuses on understanding the situation, identifying a problem and also finding a solution, Schön's (1983) reflection *in* and *on* action became significant to this research. The study made reflection stops and took stock at various points to look, think and take action. Reflection *in* action provided insights that arose during each of the steps taken in the design process while reflection *on* action arose from looking at the results of these steps. Thus, these reflections assessed the validity within the activities carried out. The first reflection is recorded at the end of this chapter.

Construct Validity was assured by identifying appropriate tools and visuals such as ADS and resource functions that were used for tracking and reflection throughout the thesis.

2.1.5. Chosen Paradigm

Section 2.1 explored research paradigms relating to design interventions, in order to explain how the research paradigms were reviewed, rejected or chosen. The suitability of these paradigms and the activities they comprised of were explored in the light of the chosen case study. Threats to the validity of the findings from such activities were also discussed. With a combination of complimentary research paradigms, the research paradigm chosen and used was Action Research via Research through Design with Naturalistic approaches within the case study context. This requires a research process that fits into the paradigm.

The next section reviews potential processes to determine if they are suitable for this research.

2.2. Research Methodology

Section 2.1 investigated methodological paradigms, which are overarching approaches to research, and explained how the paradigm for this research was chosen. Paradigms may involve several processes or methodologies, each process or methodology being a different systematic approach to responding to research problems or questions. Each design process or methodology is made up of several stages and research activities.

Methodologies can be categorised as engineering and creative design approaches; quantitative, qualitative and mixed approaches (Creswell, 2003) or sequential and parallel approaches (Green, *et al.*, 1989). Another way to look at these processes is by looking at what the processes is led by or focussed on. Cockton (2010) refers to these foci as *types of design choices* (referred to in this thesis as *design arenas*):

- *Purpose* – Why we are designing;
- *Artefact* – What is being designed;
- *Beneficiaries* – Who we are designing for and what matters about them; and

- *Evaluations* – How successful the designs are.

A design process cannot be led by *evaluations*, since a design needs to be produced first in order to be evaluated. Thus, a design process can be both led by and focussed on any one of the first three design arenas (*purpose*, *artefacts* and *beneficiaries*). Each type of design arena gives rise to its own options and arenas. This approach is also aligned to the chosen design context of disability, having to understand who the beneficiaries are, the tool to be designed, the purpose of the artefact and its effectiveness.

This section reviews potential design methodologies by separating sequential from parallel and further categorises them by their focus on design arenas. Following the review of these methodologies, this section justifies the methodology taken in this research.

2.2.1. Sequential Methodologies

This section explores sequential methodologies including many engineering and creative design approaches. Sequential methodologies originate in engineering where the emphasis was to specify problems and requirements first and thereafter carry out design and development. This section discusses a range of sequential methodologies led by specific design arenas *beneficiaries*, *artefact* and *purpose* that had potential to be applied to this research.

2.2.1.1. Beneficiary-Led/User-Centred Engineering Methodologies

Beneficiaries are theorised, or specific individuals identified as stakeholders, for a design requirement. As a research context that requires focus on potential users, Beneficiary-Led/Human-Centred Design (HCD) approaches were reviewed.

Classic engineering design refers to the process of understanding the design context, specifying requirements, designing and evaluating the artefact. This process hardly has any support to include beneficiaries during the design or development process. Such limited involvement of beneficiaries is uncommon user or human-centred design approaches, where the designers make informed decisions on the needs of the beneficiaries throughout the process.

At the start of the process, the research context was not fully understood and no potential beneficiaries had been consulted. In addition, due to the nature of the context, it was not possible to make assumptions on behalf of the *beneficiaries* to know the requirements and specifications. Therefore, classic engineering design was unsuitable and a user-centred engineering approach was considered.

A significant step in design to increase usability in engineering methodologies was proposed by Gould and Lewis (1985) who defined three principles of system design that must be followed. These principles were: early and continual focus on users; empirical measurement of usage; and iterative design whereby the system (simulated, prototype, and real) is modified, tested, modified again, tested again, and the cycle is repeated again and again. As a methodology focused continuously on users, this methodology had potential for this research. This methodology is also acclaimed as a classic approach in the Human Computer Interaction (HCI) domain and has had an impact on several ones to follow.

The focus on users was included in an engineering methodology for the first time in 1999, when the International Standards Office (ISO) 13407 provided processes for interactive systems by incorporating user centred design methods throughout the design cycle (International Standards Office, 1999). The four activities shown in Figure 2.2 were required to be iteratively carried out at the beginning of the project.

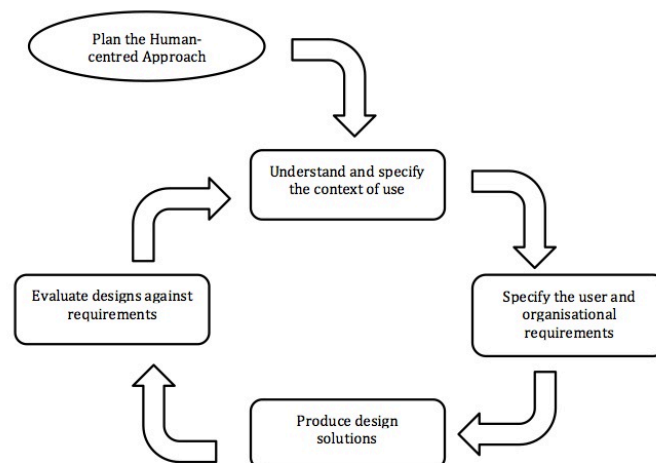


Figure 2.2 - ISO 13407

The first activity, focused on ‘planning the human-centred approach’. The second step was to ‘understand and specify the context of use’ focused on purpose, the third step,

specify ‘the user and organisational requirements’ on beneficiaries, the fourth, ‘produce design solution’ on artefact and the last, ‘evaluate design against requirements on evaluation’, which made the process sequential. The first and last activities of ISO 13407 (International Standards Office, 1999) correspond to Gould and Lewis’ first two principles and provided a more concrete structure.

The second activity maintains an engineering design approach where the focus is on the already specified requirements and design. This is similar to the classic waterfall model but is iterative, providing scope for redefining the requirements.

1. The design is based upon an explicit understanding of users, tasks and environments;
2. Users are involved throughout the design and development;
3. The design is driven and refined by user-centred evaluation;
4. The process is iterative;
5. The design addresses the whole user experience;
6. The design team includes multidisciplinary skills and perspectives.

However, in 2010, ISO 13407 was updated to ISO 9241-210, which stated the following six principles (Figure 2.3):

It also provided further iteration as shown in Figure 2.3. The blue arrows in the figure shows that at the point of evaluation, the requirement specification or design step could be repeated.

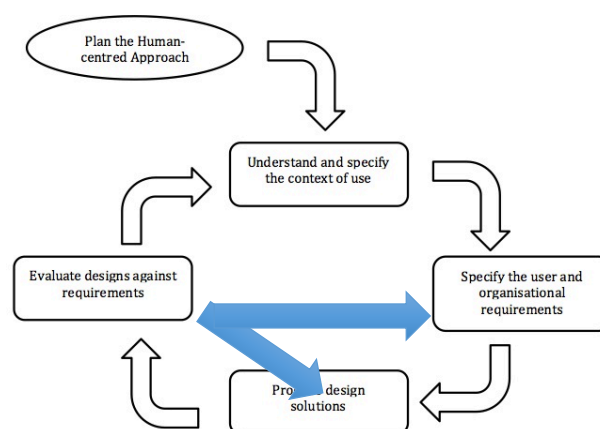


Figure 2.3 - ISO 9241-210

These principles are addressed via the same phase sequence as ISO 13407, with each phase being homogeneous, with only one activity carried out at any one time.

Although iterative, this is not a concurrent engineering methodology where different types of activity occur in parallel. The ISO 9241-210 standard remains too close to engineering waterfall models that promote project completion on time and to budget with some degree of quality. On one hand design research, being different to design practice is not restricted by budgets and competition and instead seeks knowledge output. On the other hand, these engineering methodologies are now out-dated as engineering design methodologies, where concurrent engineering is becoming more established (Cockton, 2012). In practice, this meant while a research design activity was underway, a research activity could be conducted in parallel.

ISO 9241-210 (2010) is an example of Human-Centered Design (HCD), a beneficiary led process of product development that starts with users and their needs rather than with technology. Its goal is to develop a technology that serves the user, where the technology fits the task. HCD methods are used in a variety of domains such as environment design, service design, product design and interface designs. HCD product development requires developers who understand people and the tasks they wish to perform. Interface researchers use methods including observations, interviews, surveys, contextual inquiry and design, existing literature or participatory design and systems design, some of which were used in this research and are described extensively in Section 3.3 (Limbourg *et al.*, 2001, Bevan, 2003).

An approach related to HCD is psychology led design, which is a theoretical approach that is presented in the form of models and is based on secondary data. An example of such a theoretical HCD approach is by Carey and his team (2007) in their Accessibility Information Matrix (AIM) where they discuss how Norman's (1990) model, and its various stages of action could be used to access information for individuals with disabilities. The seven steps in Norman's (1990) model are as follows:

1. Forming the Goal
2. Forming the intention
3. Specifying an action

4. Executing the action
5. Perceiving the state of the world
6. Interpreting the state of the world
7. Evaluating the outcome

Carey and his team (2007) break down the goal of activity into sub goals of acquisition, perception, cognition, integration, intent, navigation, creation and interaction to focus their research. Their research claims that these AIM sub goals could be applied to existing problems, user tasks performed, reference needs of disability groups, and identify appropriate solutions. AIM can also be used to guide the design of new technology and techniques for accessing information. However, secondary data will not provide a solution that does not yet exist. Data alone will be insufficient for this research and therefore this methodology is not appropriate.

One beneficiary led approach that is based on primary data is contextual inquiry and design. It is used in any environment where data can be gathered from individuals while they work and can drive the definition of a product or process, while also supporting the needs of teams and their organizations. Contextual design enables researchers to gather detailed data about how people work and use systems, and generate systems designs from knowledge of customer work (Beyer and Holtzblatt, 1998; Clarke and Cockton, 1999). Contextual design process includes:

1. Contextual inquiry;
2. Interpretation session;
3. Data consolidation;
4. Visioning;
5. Storyboarding;
6. Product and system development;
7. Paper mock-up interviews and
8. Interaction, visual and industrial design.

While the literature presents this as a sequence, these activities can be used both independently and in parallel. From the contextual design process, contextual inquiry was used in this research through observation and interviews and as well as paper mock-up interview/prototyping.

2.2.1.2. Artefact Led Approaches

Potential methodologies that focus on systems development are reviewed in this section. An artefact is as an object usually made by humans and something that occurs as a result of the preparative or investigative procedure (Oxford Dictionary, 2014). In an artefact led approach, the artefact or technology is an assumed solution to a need.

An approach to developing a software, artefact (Abrahamsson *et al.*, 2002) may include techniques such as extreme programming (XP), Scrum, Crystal family of methodologies, Feature Driven development, The Rational Unified Process, Dynamic Systems Development Method, Adaptive Software Development, Open source Software Development and several other methods. Some of them are described as follows:

1. Extreme Programming (XP) consists of five phases: exploration, planning, iteration to release, productionising, maintenance and death (Beck & Andreas, 2005). The process works with customers to identify the features that are required in each of the releases and follows through until the customer no longer needs the product. Each of these phases can consist of a scrum framework.
2. Scrum is a real time decision-making process where multiple small teams work in an intensive and interdependent manner in an adaptive, quick and self-organizing product development process (Takeuchi and Nonaka, 1986). The term derives from rugby. The three steps of Scrum are pre-game, development and postgame where each cycle is known as a sprint. The aim of this approach is to deal with constantly changing and unpredictable requirements in systems development. Once a complete design solution has been built, based on regular feedback or requirement changes, scrums may be used. This is a type of agile process.
3. Agile is a timed, iterative and incremental process that is used within routine software development (Leffingwell & Widrig, 2010). In an agile development process, duration of iterations (known as sprints) are fixed but the requirements evolve and are captured; each feature is completed before moving on to the next; evaluations are embedded within each cycle and different teams are assigned and empowered to make decisions.

The development of the design solution in this research was outsourced to an independent programmer for development and was closely monitored by providing interface designs, content and interaction designs. An artefact led approach was appropriate within the initial development phase, but for it to be design research (rather than design practice), a broader approach with space for the production of knowledge was necessary. Therefore, while it could be artefact focused at times, this focus would also need to shift to other design arenas.

Another artefact led approach is Exploratory Programming, which is carried out when the specifications or requirements of an artefact for development are unclear and there is an opportunity to interactively debug without a process or constraint. Programming languages such as Python, Lisp, or Prolog can be used for this purpose. This may be a suitable approach if it is not possible to initially achieve a well-developed understanding of the design situation. However, programming itself is not expected to increase the understanding of the design problem. The development of the *artefact* in this research was outsourced to an independent developer, as this research was not reliant on the developer's understanding of the design situation. The researcher is not a programmer and the programming was not part of the researcher's contribution to knowledge and therefore this approach was discarded.

Yet another artefact first approach that uses the modelling of the interaction of an artefact is Cassidy and his team's (2004) model-led approach, where a user-centred interactive approach for accessible system designs is undertaken. This approach builds on Accessibility Interaction Modelling (AIM) and enhances identification of specific problems faced by motor-impaired individuals, together with those who are involved in their wellbeing, and takes them into account when designing mainstream systems. As this research started with an undefined design solution, this methodology was deemed unsuitable for this study.

2.2.1.3. Purpose Led Approaches

As initial activities were carried out, the purpose for design solution became clearer. According to the Oxford Dictionary (2014), "purpose is the reason for which something is done or created or for which something exists". In a purpose-led

approach, the purpose leads the research and therefore the focus initially is on identifying the purpose and then meeting the requirements that it suggests.

One purpose led approach is the Value-Centred Design framework (also known as Value-Centred Development or VCD), which was developed to take HCI beyond usability evaluation and contextual fit to focus on value identification, delivery envisioning and impact assessment. Cockton (2005) proposed a framework for VCD structured around four activities:

1. Opportunity identification, where the focus is on beneficiaries and purpose, which is the intended value;
2. Design is the focus on the artefact;
3. Evaluation establishes the impact of connecting the artefact with purpose and
4. Iteration revisits and addresses evaluation, findings and recommendations.

Another purpose led approach is Value Sensitive Design, which involves the design of technology being sensitive to ethical values throughout the design process (Friedman *et al.*, 2002). This approach focuses on moral values, norms and moral considerations of the stakeholders as part of technological design, research and development. Better still, a system responding to the values of the stakeholder, that meets the needs and wants of all possible stakeholders will deliver extensive worth.

Worth has provided a better and balanced focus than VCD (Cockton, 2006) as worth creates value, increases benefits and reduces risks and costs. Worthwhile systems are those which have an adequate *worth* (defined as a balance of value over costs) meaning that the design delivers sufficient benefits to outweigh costs of ownership and usage to the beneficiaries (Cockton, 2008a). Designing for worth is designing “for people to buy, learn, use or recommend an interactive product, ideally most or all of these” (Cockton, 2006, p.169). Exploring each stakeholder’s needs, wants, likes, dislikes and technical capabilities could identify these values.

This approach was embraced for this research and costs, risks and benefits were continuously evaluated throughout the research in order to maintain the balance of worth.

2.2.1.4. Hybrid Approach

A variant of an engineering methodology that was potentially useful and used for this research was the Microsoft Research (MSR) extended design cycle (Microsoft Corporation, 2008a) that provides a process to address research problems (Figure 2.4). This warrants a separate section as it has more than one design arena leading the design.

The cycle breaks the research process into five stages *Understand*, *Study*, *Design*, *Build* and *Evaluate* that can validate the instrumentation, data gathering, designs, findings and evaluations.

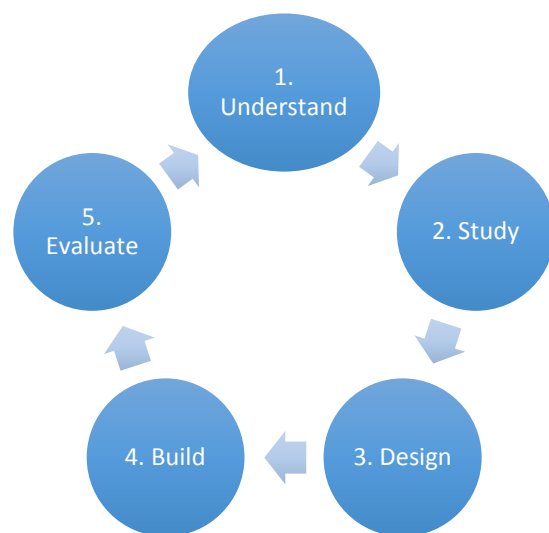


Figure 2.4 - Microsoft Research Design Cycle

The *Understand* stage focuses on the values of real users and stakeholders through broader Human Computer Interaction domains such as Sociology or Psychology. This stage provides a framework to guide in depth research in the second stage, *Study*. This in turn guides the research towards identifying clear research goals, which would be the *Design* stage. This is the creative stage of the cycle where the user goals are set. In the next stage *Build*, creative techniques such as wireframes and stories are used to visualise the proposed design solution. All development is done during this stage. The *Evaluation* stage involves any user testing method to check if the user goals identified in the *Design* stage have been achieved.

This research adopted this methodology between 2010 and 2012. During this time the five stages were mapped against research questions and activities. Due to the realities

of concurrency in activities, MSR extended design cycle was also modified to fit to the activities. As with ISO 9241-210, the MSR extended design cycle is also iterative, but it does not permit concurrent activities. Adhering to it became increasingly difficult so it was discarded as not suited for a RtD process.

2.2.1.5. Summary

The methodologies reviewed in the above section show how design arenas are explored sequentially when the methodology is either in led by or centred in a design arena. Addressing all arenas requires shifting design foci rather than an approach that is centred or led by a single type of design choice making it challenging to use a sequential methodology. These continuously shifting foci require a post-centric design approach that allows for multiple foci and foci shift during a single design process. Being committed to data driven RtD process, going beyond what is required practice, will demonstrate *generosity* of the design process. These findings may be *beneficiary*, *artefact* or *purpose* led or focused and as such, worth may be a suitable integrator. Therefore this RtD process was worth-focussed rather than being centred on or around singular design arenas.

Continuous focus, on potentially all design arenas, although in varying priority, is required simultaneously so as to not to lose focus on any of the design arenas. Therefore, this hybrid approach also called for design arenas to be advanced in parallel rather than simply sequentially. The next section explores how design arenas could be explored in parallel and led by different design arenas at different stages of the process.

2.2.2. Parallel Methodologies

This section explores several parallel methodologies relevant to the research. As stated above (Section 2.2.1), a parallel methodology is one where multiple activities are conducted simultaneously, or when there is more than one *design arena* focused on at the same time.

2.2.2.1. Concurrent Engineering

Concurrent Engineering (CE) is a parallel methodology that has been practiced since the 1980s in product design, particularly in the military and aerospace domains, for example, European Space Agency, NASA and Boeing. While traditional sequential engineering approaches such as waterfall are normally carried out sequentially, CE considers all lifecycle issues simultaneously through a tight integration of evolutionary iterations and is normally carried out collaboratively (Ma *et al.*, 2008).

Typical characteristics of CE could be multi-organisational teams, distributed product realisation and integrated project management. CE is visualised according to the activities that are carried out in parallel and therefore varies according to the project. Figure 2.5 shows two examples.

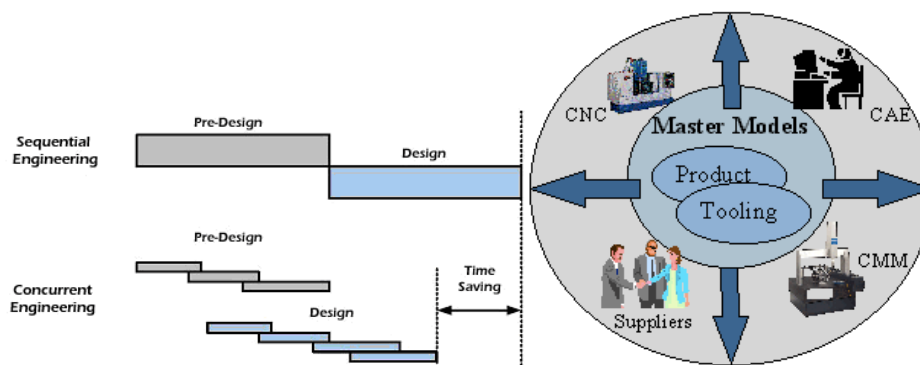


Figure 2.5 - Concurrent Engineering Life Cycle (Source: <http://tinyurl.com/peou47y> and <http://www.1cadcam.com/Consulting.html>)

CE can also be perceived as a number of design modules that are executed in parallel. As this approach would normally have several teams working on individual features of the artefact in parallel. It is expected to reduce the time line and be more efficient. However, as each feature is part of a larger system where teams are developing parts of the system separately, they need to be balanced and integrated without overlaps (Hoedemaker *et al.*, 1995). Being an engineering approach, CE is artefact focused and feature led.

While a concurrent approach is suited to this design research context, a wholly engineering approach is not. RtD provides the opportunity for both problem and solution spaces to shift, and for both substantive and practical knowledge obtained to lead the process.

2.2.2.2. Keller's Methodology

Keller's (2005) doctoral study used both Research *through* design and Research *for* design approaches to explore how designers use collections of visual material for inspiration and how new media tools help the designer interact with this material. He visualised the interweaving of parallel research activities and practical exploration within the RtD paradigm in a form that highlighted the interweaving of each research focus (Figure 2.6) at a single point throughout the research.

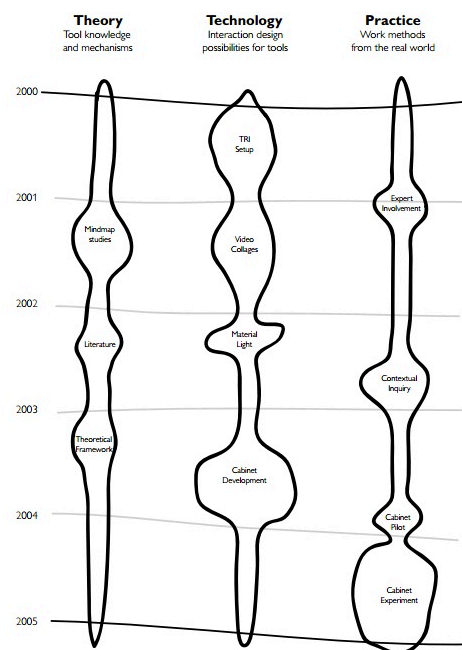


Figure 2.6 - Keller's Process

These stalactite shapes visualise how a design research process can have multiple foci or multiple activities at the same time, in parallel, have pauses and with varying foci. Keller illustrated how his foci on theory, technology and practice progress through the phases of a RtD process were not predictable, homogenous or manageable.

Keller's approach is not directly applicable to this research as there is little relevance to tracking theory, technology and practice. However, his research provides a concept that can be used to visualise the changing foci on design arenas over the entire process. Since the anticipated foci can be different to the realised foci, this concept was extended to track the anticipated design arenas and foci against the realised design arenas and foci.

2.2.2.3. Co-evolution and Primary Generators

Cockton (2013b) explains how design, as a complex process has continuously evolving details at various points of the design process (a concept, sketch, prototype, final artefact, or manufacture). Complex problems, such as the chosen case study that require being intelligently undecided about them, are known as ‘wicked problems’ (Conklin, 2005).

Cross (2000) explains the need for a design process to repeatedly diverge and converge to continuously seek new ideas, widen the search and starting points before finally converging to provide a detailed design proposal. Cross’ model includes four steps: exploration, generation, evaluation and communication. Generation and evaluation are iterated and both problem and solution spaces co-evolve. Cross also referred to Schön’s (1983) work on reflective practice as the space for creative problems and solutions where design-related choices are made to lead to a design solution. This works well with the chosen RtD paradigm as the design space is sufficiently open for both parallel and shifting needs of the research.

As seen at the beginning of Section 2.2, the types of design arenas in a design process address: *purpose*, *artefact*, *beneficiaries* and *evaluations*. Darke (1979) identified preliminary *artefact* choices as the *primary generator*. She presents the process of design as *generator-conjecture-analysis* where conjecture conceptualises a particular stage of a design process and the *artefact* concept or objective that generates a solution is called the *primary generator*.

Darke explains that as part of the designer’s cognitive structure, it is the *primary generator* that generates the solution in a design process. She also states that the designers may not be aware of the *primary generator* leading the design during the process and being the aim or focus of the phase. This research started by assuming an artefact would be built to produce a solution to the chosen design situation, which would make that the *primary generator* according to Darke. However, within the practice of RtD where both problem and solution spaces co-evolve, a single *primary generator* cannot be emerges, and this may not be the envisaged artefact.

Keller (2005)'s visualisation showed a balance of theory, technology and practice. Cockton (2013b) described a similarly balanced approach for design arenas. He explained how balanced design arenas must integrate to provide a solution, where the success of the solution cannot be guaranteed by an isolated arena.

In contrast to sequential methodologies that were either centred or led by a design arena throughout the process, parallel methodologies tend to have a primary design arena focus and other design choice foci at each reflective point. In addition, anticipated foci may not correspond to what was actually iterated or discovered.

Reflection points in RtD can expose how both problem and solution spaces evolve within parallel activities, demonstrating progressive instantiation (Dorst & Cross, 2001).

2.2.2.4. Reflection

Section 2.1.3.2 showed that there are no suitable existing models for reflection within a RtD process. This section reviews several frameworks for reflection and how they can work together in the chosen RtD context.

Design work occurs within *Concrete Design Setting* (CDS), with evolving design arenas and the *connections* between them. An abstraction of such CDSs is an *Abstract Design Situation* (ADS). The four identified design arenas can be used as a framework for reflection at reflective stops in the RtD process.

ADS is a reflective concept that is suitable to evaluate the resources used. This thesis records planning of functions (of resources) and looks back at findings at the end of each phase, generating a new ADS via connections, thereby being *analytical*. The reflection also compares these findings against the anticipated findings, which leads to *evaluation*.

Cockton (2010) relates ADS to *meta-principles* and restricts meta-principles to an evaluative role. These meta-principles are: committedness to design scope and to design principles, inquisitiveness, tenacity, expressivity, informativeness, performativeness, propulsiveness, desirability of artefacts, viability of purpose, inclusiveness for beneficiaries and improvability from evaluations. Resource

functions are both descriptive and support evaluations as meta-principles are assessed through resource functions (Cockton, 2013a).

Cockton (2009a, p.2225) states that ‘Meta-principles must be *instantiated* to support a specific project. This can be achieved by a process of progressive instantiation’.

Instantiation is the process where problems are exposed and solutions are found.

Cockton (2009) describes the process of progressive instantiation as committing to value systems; making it explicit and informing development frameworks. This is a useful description of the reflection point but there has been no follow up since Cockton’s research into meta-principles shifted to resource functions.

While completed resources have specific functions at specific points in a research process, reusable resources have varying extents of completion and are adaptable and thus, design work completes incomplete re-usable approaches.

This research therefore uses the vocabulary of resource functions to identify potential functions and track progress of each design arena by evaluating the actual work done at the end of each phase in the context of ADS and meta-principles for design.

Cockton (2013b, p.13) recommends an open vocabulary for describing these resource functions as follows.

- *Adumbrative* (rough outline of an approach’s scope)
- *Ameliorative* (an approach’s guiding values)
- *Inquisitive* (finds out stuff)
- *Directive* (systematically guides design work)
- *Expressive* (gets stuff down)
- *Informative* (puts stuff in)
- *Performative* (spreads stuff out)
- *Invigorative* (spurs things on)
- *Protective* (keeps things up)
- *Integrative* (pulls stuff together)

Resource functions provide a basis for recording and auditing Balanced (scoping), Integrated (between and within design arenas) and Generous (choices for *purpose*)

(BIG) design. The functions of these resources can also be described by other synonyms. Resource functions will be used as a reflection tool at the end of iterations within the RtD process.

Working to Choose (W2C) framework also provides a conceptual structure for reflection. Methods are resources that are used at various points in a research process. Resource functions are part of Cockton's W2C framework, a "systematic conceptual structure that supports analysis, assessment and improvement of design work" (Cockton, 2013a, p.1). W2C provides a framework for understanding the process of identifying options, strengthening options and evaluating them until the design solution is achieved.

W2C framework combines Abstract Design Situation (ADS) meta-principles for designing and resource functions to be used:

Analytically: to decompose design settings, methods and approaches;

Evaluatively: to critique specific design settings, methods and approaches;

Generatively: to develop supportive design approaches and resources for them" guided by *resource functions*, *meta-principles* and *ADS* (Cockton, 2013b, p.11-12).

Cockton (2011) combined engineering, applied arts and user centred design disciplines to focus on human outcomes (Cockton, 2011) to propose Balanced, Integrative and Generous (BIG) design (Cockton, 2010).

A BIG design is a result of reflection. To realise a BIG CDS, a continuous iteration of all four design arenas, through design ideation, user studies, evaluations and refinement of purpose, is required. This will often be opportunistic, evolving through one design phase at a time. Each phase is characterised by the identification of the ADS at the end of activities where a reflection takes place and the design problem is reframed continuously. Activities recorded in Chapters 4-9 also showed how activities and iterations are integrated.

2.2.2.5. Total Iteration Potential

Cockton (2005) explains how HCI as a domain shifted focus from being system-centred in the 1970s, user-centred in the 1980s, context-centred in the 1990s and value-centred in 2000s. In the 2005, Cockton proposed a Value centred development framework, continuing a centric approach. He goes on to say that sequential methodologies could have multiple foci within a process. While this is substantially true in acknowledging system, user, context and values at the beginning of planning the process, it is not possible to iterate them fully without having multiple activities with different foci simultaneously. This effectively means only post-centric parallel methodologies can really have *total* iteration potential.

As seen at the beginning of Section 2.2, design arenas comprise *beneficiaries*, *evaluations*, *artefact* and *purpose*. This research attempts to understand the *purpose*, *beneficiaries* and the appropriate *artefact* in order to transform a current situation to an ideal or preferred situation. Therefore, the *purpose* needs to be made clear and extended through research; the findings need to be *evaluated* every step of the way; *artefacts* need to be identified and potential designs explored. En route to identifying the problem and the right design solution, representations and *artefacts* should be generated, effectively researching through design. This design research process would provide empirical grounding and also ideation, in identifying alternative design solutions. This too would be clearly different from engineering problems where it is the norm to summatively evaluate solutions. The *artefacts* should be designed and *evaluated* formatively and iteratively towards attaining the preferred design situation (Zimmerman *et al.*, 2007).

An ADS exposes balance and integration at different reflection points. It comprises separate design arenas that may or may not have connections between them (Figure 2.2). The letters in Figure 2.2 refer to the four design arenas *beneficiaries* (B), *evaluations* (E), *artefact* (A) and *purpose* (P), each corresponding to a separate design arena.

Only when a single design arena does not lead the research sequentially, and reflection continuously reframes the focus can there be *Total Iteration Potential*

(TIP), (Cockton, 2006). Total iteration means iteration of any design arena in any order or combination.

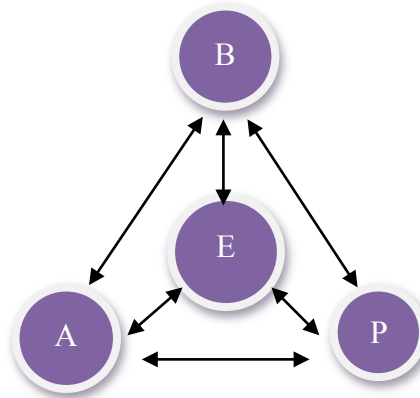


Figure 2.7- Connections to Connections

ADSs express high level scope for design processes, approaches and resources (Cockton, 2013b). The activities within each design research phase can be planned with the intention of possible stabilisation into sequential methodology and conclude with a reflective point, where the new ADS resulting from the design work done in that phase is identified.

An RtD process needs to be planned with the assumption of addressing more than one design arena type in parallel, which should enable TIP via planned open phases where reflective stops mark the end to phases, providing opportunity for decisions making on the methods used in the subsequent iterations. This thesis tracks ADS at different levels of abstraction at the various reflective stops that it makes.

As the research approach for the chosen case study was reviewed, planned and executed at different levels, a coherent extent within design practice ranging from the most abstract (*design paradigm*), through *design process*, *process stage* and *design approach* (completed resources), to the most concrete (*design resource*) is referred to as a *Design Chunk* in this research. *Design Paradigm* refers to the most abstract form of *design chunk*, i.e, the design milieu for a design process and Tools used within a *design process* (a structure for design activities made up of stages) is referred to as a *Design Resource*. A Glossary has been produced as an aid for the reader to continuously refer to these terms, abbreviations and definitions.

2.2.3. Chosen Methodology

Having reviewed and sometimes attempted to use the methodologies in this section, a parallel methodology was deemed to be the most suited to this research. This methodology was worth focused, as it was not restricted to be led by a single design arena. Instead, it could shift at any point and continue to connect to the other design arenas. It did not have to be tied to a set process. This provided an approach that was broad enough to fit in with the chosen RtD paradigm. This thesis further uses Keller's approach and visualisation of how theory, technology and practice combine, but with Cockton's idea of design arenas to track balance and identify the primary generator at the reflection points at the end of each of the iterations. Based on the tracking, it also enabled review of Darke's position on primary generator.

The next section explores design and evaluation methods that were considered for activities within the chosen methodology.

2.3. Potential Methods

This section explores the choice of methods supported by Cockton's (2013a) schema of *resource functions*, explained in Section 2.1.3.3.

The following Sections 2.3.1- 2.3.5 explore methods for design and evaluation activities that focus on *beneficiaries*, *artefact*, *evaluation* and *purpose* and make connections to other design arenas. The *functions* of the *resources* are recognised as primary, potential and unlikely for each of the methods/resources discussed. The functions are:

- *Adumbrative* (rough outline of an approach's scope)
- *Ameliorative* (an approach's guiding values)
- *Inquisitive* (finds out stuff)
- *Directive* (systematically guides design work)
- *Expressive* (gets stuff down)
- *Informative* (puts stuff in)
- *Performative* (spreads stuff out)
- *Invigorative* (spurs things on)

- *Protective* (keeps things up)
- *Integrative* (pulls stuff together)

2.3.1. Methods for Data and insights collection for Beneficiaries

Activities used to collect data and insights to gain an in-depth understanding of a case study environment and to gather information from participants are reviewed in this section.

2.3.1.1. Participant Observation

Participant observation is a method in which research is carried out in a natural setting to find out what participants do, instead of what they say they do (Berger, 2000). Participant observation is primarily an *inquisitive* activity where it finds out information, but the findings also have the potential to *inform* the design work where it contributes and help *scope* out (adumbrative) an outline of the approach.

Table 2.1 - Functions of Participant Observation

Resource	Primary Function	Potential Functions	Unlikely Functions
Participant Observation (Activity 2)	Inquisitive	Adumbrative Ameliorative Directive Informative Invigorative Protective	Expressive Integrative Performative

Participant observation is an appropriate method for naturalistic inquiry, a research approach used to obtain substantive knowledge, as explored in Section 2.1.2. The setting, participants, nature and purpose of the group, the behaviour of people in the group, the frequencies and durations of behaviours in the group and recording for observation are significant considerations while applying this method. In addition, videos recorded while participants use an artefact in its intended setting can be viewed as a form of participant observation. However, this is not an appropriate method to understand the reasons for the behaviour in the observation and therefore needs to rely on additional methods to obtain such information.

2.3.1.2. Surveys

Surveying can be both analytic and descriptive. This method is *inquisitive* and *informative* in function and is used to collect and analyse social data through interviews or questionnaires. These are often highly structured and detailed. Information can be obtained from a numbers of respondents using this method. While undertaking this method, the participant is assumed to be a representative of your target population (Berger, 2000). Once a substantial amount of context has been identified, surveys can be used for confirming requirements and identifying any missing data.

Table 2.2 - Functions of Surveys

Resource	Primary Function	Potential Function	Unlikely Function
Questionnaire (Activities 9-11) Interviews (Activities 1, 3, 7)	Inquisitive	Directive Expressive Informative Invigorative Performative Protective	Adumbrative Ameliorative Integrative

When surveys are conducted in the form of interviews, they could be structured, semi-structured or unstructured. Surveys need to be planned with rigour and could invite responses for both open and closed questions, but they may also be opportunistic.

Face to face surveys, in the form of interviews also provide the opportunity for any demonstrations prior to asking question and be *performative*.

As part of the design process, when surveys take the form of questionnaires, they may take several forms of questions including yes/no, one word responses, Likert scales, multiple response choices and descriptive responses (*inquisitive*). They are usually highly structured, where the survey requests views and information (*informative*). Questions may be asked with a stem or lead up to the questions and be *invigorative* for respondents. The responses received from participants to these questions will be *expressive*.

If the survey is piloted ahead of fielding, it would be *protective* where the pilot assures the question is clear and makes sense to the respondent.

Surveys can have at least four functions, beyond being *inquisitive* resulting in being *informative*. The created survey and the results from the survey are the main potential resources.

2.3.1.3. Desk / Secondary Research

Desk / secondary research focuses on existing literature, as described in Section 2.1.1 and is predominantly *informative*. It has the potential to inform the research of existing information and guide the primary research activities.

Table 2.3 - Functions of Desk/Secondary Research

Resource	Primary Function	Potential Functions	Unlikely functions
Desk/Secondary research (Chapter 3, Activity 5)	Informative	Directive Adumbrative Ameliorative Invigorative Integrative Protective	Expressive Inquisitive Performative

2.3.2. Methods for Expressing Findings on Beneficiaries

The data gathered using methods described in Section 2.3.1 are presented throughout Chapters 5-9 using methods described in this section for effective communication.

2.3.2.1. Personas

Personas are profiles or abstract representations of users that help in the design of interfaces (Cooper, 1999; Pruitt and Adlin, 2006). During the design process, personas are treated as users with names and faces and the design team tries to satisfy their aims and objectives. Personas based on field data, are considered richer and more complete than a mere description of a user (Holtzblatt *et al.*, 2005). The function of this resource is primarily to *express* what is believed to be norms and not exceptions. Personas can connect people with purpose and technology in the design of Socio-Technical Systems They also support *integration* of findings by pulling

together information from a variety of activities. A common known problem with personas is that they may be built on information that is not firsthand (Pruitt and Grudin, 2003). The personas in Chapter 7 build on both secondary and primary research. Olsen (2004) provides a framework that is *directive* and *inquisitive* to systematically develop personas, which is adopted for this research context.

Table 2.4 - Functions of Personas

Resource	Primary Function	Potential Functions	Unlikely Functions
Personas (Activity 12)	Expressive	Ameliorative Directive Inquisitive Integrative Protective	Adumbrative Informative Invigorative Performative

2.3.2.2. Contextual Design Models

Findings from Contextual Inquiry (which is the first step in Contextual Design process) can be *expressed* using the following models (Holtzblatt *et al.*, 2005):

- *Physical* models represent the participant's environment to show the tasks in context;
- *Sequence* model shows the step by step process of the participant completing the tasks. It will record the steps, triggers and the intent for the step;
- *Artifact* models are representation of things used in the process;
- *Flow* models show participants' responsibilities, communication and coordination to complete the flow model; and
- *Cultural* models reveal ethnographic influences on participants.

Table 2.5 - Functions of Contextual Design Models

Resource	Primary Function	Potential Functions	Unlikely Functions
Contextual Design Models (used and discarded)	Expressive	Directive Informative Invigorative	Adumbrative Ameliorative Inquisitive Integrative Performative Protective

These models can be useful to understand the physical design context, the sequence of tasks that are carried out within this context, the artefact that is used to carry out these tasks, the work flow and external cultural influences. While this seems relevant at first, the chosen design context includes multiple environments and multiple environment related tasks, making the contextual design context more complex. This varies further as what is designed is a virtual artefact independent of or complementary to the physical environment. Therefore while contextual inquiry was conducted, it was not fully executed through to producing all the models.

2.3.2.3. Sentence Completion

An approach reported by Cockton and his team (2009) was sentence completion that was used as part of the VALU project in support of worth mapping (please see [Section 2.3.3.5](#)). Sentence completion is an approach from consumer psychology and is used to complete information in written form with the participant's immediate reactions. Sentence completion is a value elicitation technique. This approach was considered to be a viable, methods to elicit values for completing and revising worth sketches. However, values elicited from surveys and interviews were instead used to fulfill the same function.

Table 2.6 - Functions of Sentence Completion

Resource	Primary Function	Potential Functions	Unlikely Functions
Sentence Completion (not used)	Inquisitive	Directive Informative Invigorative	Adumbrative Ameliorative Inquisitive Integrative Performative Protective

2.3.3. Methods for Artefact Design and Co-ordination

In the following methods, while the focus appears to be on the *artefact*, few design methods in HCI can be purely *artefact* focused. Designing methods also co-ordinate *artefacts* with *purpose* and *beneficiaries*. They thus have *integrative* functions.

2.3.3.1. Requirement Specification

A requirements specification is a detailed document that *expresses* both functional and non-functional requirements. It can also be *ameliorative* where the requirements function as guiding values for collaborative work or *directive* where the requirements systematically guide the design process when development is done independently or outsourced.

Table 2.7 - Functions of Requirement Specification

Resource	Primary Function	Potential Functions	Unlikely Functions
Requirement Specification (Activity 13)	Expressive	Adumbrative Ameliorative Directive Protective	Informative Inquisitive Integrative Invigorative Performative

2.3.3.2. Wireframes, Workflows and Prototypes

Wireframes are sketches of an interface that describe screen layout and visually *expresses* the structure highlighting placements, groupings, priorities, terminology and other information architecture related factors (Kelway, 2008). They can be low-fidelity where the sketches are created manually or high-fidelity where interaction is also digitally included. Wireframes focus solely on the design arena of *artefacts*.

Table 2.8 - Functions of Wireframes, Workflows and Prototypes

Resource	Primary Function	Potential Functions	Unlikely Functions
Wireframes, Workflows and Prototypes (Activity 14)	Expressive	Directive Invigorative Informative Protective	Adumbrative Ameliorative Inquisitive Performative Integrative

Workflows that show the sequence of activities, and Unified Modelling Language (UML) diagrams that model the interaction within software, can also be used as an aid to designing interactions.

Prototypes represent real user interfaces and are easier to design, test and modify. They can take the form of user guides, paper simulations, software-based simulations, or an early version of software or the system to be replaced (Gould *et al.*, 1987). Cassidy and his team (2005) also developed a test rig to create prototypes to assist in identifying capability, accessibility and aspiration.

Chapter 7 recorded design ideas in sketches and wireframes. The inspiration came from Linowski's (2009) Wireframing ideas. They were provided to the developer for the first version of the development. Detailed screen by screen designs were provided for the second version.

2.3.3.3. Card sorting

Information Architecture is the structure of content and that includes organising and labelling of navigation systems within a website (Barker, 2005). Card sorting is an *inquisitive* approach carried out to identify the structure of the website when participants are asked to write down keywords they would look for in a website and arrange them in the order they would expect to find them. This is a co-ordination of *beneficiaries* and *artefact*, and is *informative*.

Table 2.9 - Functions of Wireframes, Workflows and Prototypes

Resource	Primary Function	Potential Functions	Unlikely Functions
Card Sorting (Activity 14)	Inquisitive	Directive Expressive Informative Invigorative	Adumbrative Ameliorative Integrative Performative Protective

Once the activities that the potential users would be completing on the interface were decided, a card sorting exercise was carried out as part of the design to organise the options on the interface.

2.3.3.4. Co-operative Design

Co-operative Design also known as Co-Design or Co-Creation refers to collaborative design and *integration* between the designer and the user, who may be a non-designer (Sanders & Stappers, 2014, p.5-14). It is a collaborative innovation approach with

design activities where stakeholders work together to develop solutions for problem spaces. With stakeholders co-designing, it reduces the demand on the designer to understand the subject matter of their design and blurs the difference between the roles of designer and user. Co-design was used in this research for pre-populating the content of the artefact.

Table 2.10 - Functions of Co-operative Design

Resource	Primary Function	Potential Functions	Unlikely Functions
Co-operative design (Activity 20)	Invigorative	Ameliorative Directive Expressive Informative Inquisitive Performative	Adumbrative Integrative Protective

2.3.3.5. Worth Sketches and Worth Maps

Worth sketches and maps are methods used to co-ordinate design choices. Worth mapping is a method within HCD that *integrates* design options. Existing reports of worth-focused approaches are restricted to the use of single methods, either to identify potential design *purpose*, or to co-ordinate this with identified options for designed *artefacts*. For example, Weijters and Muylle (2009) used Reynolds and Gutman's (1979) Means-End Chains to *express* value maps of their subjects. Cockton and collaborators at Microsoft Research (2009a) used this as a basis to develop a worth map and understand stakeholder values (*purpose*) from multiple perspectives, and associate these with proposed features (*artefact*) and qualities for a novel family archiving system. Cockton (2008) used worth maps to record *purpose* and *artefact* at different points in the design process and Otero and José (2011) used Cockton's worth maps to co-ordinate development of an *artefact*. However, these worth maps do not include information on *beneficiaries* or *evaluations*. They were *expressive* in visualising the design options and *invigorative* by being a creative thinking aid to the designer during the design process.

Kampurri (2011) also used value maps that *expressed* potential design *purpose*, in a study of cross-cultural interaction design but this did not result in potential design

interventions. Zaman and Abeelee (2010) explored the usefulness (*purpose*) and feasibility of ‘laddering’ with young children in user experience evaluations. This produced several visualisations similar to worth maps or value maps, but no complete development process has been documented so far.

Worth sketches and maps were used in this research to integrate findings at four points to assess the relationships between *artefact* features and design *purpose*, with a potential to be *adumbrative* (that outline a scope), *ameliorative* (as guiding values), *directive* in systematically leading design process, *expressive* in getting the information down explicitly and *invigorative* by spurring things on as the process moved towards a more concrete setting. Thus, worth sketches have the potential for at-least five functions.

Table 2.11 - Functions of Worth Sketches and Maps

Resource	Primary Function	Potential Functions	Unlikely Functions
Worth Sketches and Maps (reflections)	Integrative	Ameliorative Directive Expressive Adumbrative Invigorative	Informative Inquisitive Performative

2.3.4. Methods for Evaluation

The data gathered and consolidated were evaluated prior to development. Following development of the interface, further evaluations were conducted for improvement.

2.3.4.1. Comprehensive Assistive Technology (CAT) Model

The CAT model is discussed in detail in Chapter 3 (Section 3.2.5). This model is based on The International Classification of Functioning, Disability and Health (ICF), is disability focussed and can be used for the following purposes (Hersh & Johnson, 2003, p.272). This also co-ordinates all four design arenas:

1. identifying gaps in AT provision (unsupported *purpose*);
2. evaluating existing AT systems (*evaluation*);
3. supporting design and development of new AT devices (*artefact*); and
4. supporting Design for all (adding *beneficiaries*).

This resource is primarily *expressive* in organising the identified information and can be *ameliorative* by supporting improvements in accessibility, *adumbrative* in scoping the research and expose *inquisitive* and *informative* when any gaps in knowledge. Once substantial primary data was gathered, the CAT model was used to evaluate the findings and identify any potential available solutions or gaps using a systematic structure.

Table 2.12 - Functions of CAT Model

Resource	Primary Function	Potential Functions	Unlikely Functions
CAT model (Activity 8)	Expressive	Adumbrative Ameliorative Directive Informative Inquisitive Integrative Protective	Invigorative Performative

2.3.4.2. Usability Inspection Methods

Cognitive Walkthrough is a type of usability inspection method where, based on the purpose and tasks intended in the interface, the designer walks through the interface. At each step of the task, the evaluator needs to check the following points (Wharton, *et al.*, 1994):

1. Will the user try to achieve the right effect?
2. Will the user notice that the correct action is available?
3. Will the user associate the correct action with the effect to be achieved?
4. If the correct action is performed, will the user see that progress is being made toward solution of the task?

This activity is primarily *inquisitive* when asking questions to find out information and the responses can *directive* for obvious steps and *invigorative* in spurring on the responses when the steps are not clear and *informative* overall. The evaluator provides feedback (*informative*) to the developer based on the outcome of these questions. This method was used for the evaluation of the first version of the artefact and the feedback was provided to the developer.

Table 2.13 - Functions of Heuristic Evaluation

Resource	Primary Function	Potential Functions	Unlikely Functions
Heuristic Evaluation (Activity 17)	Inquisitive and Expressive	Directive Informative Protective	Adumbrative Ameliorative Inquisitive Integrative Invigorative Performative

Heuristic evaluation is a usability inspection method that is often used as an inexpensive usability engineering tool. Heuristic evaluation involves having a product analysed independently by multiple evaluators who understand the product's goals, and have good knowledge of established usability guidelines. These evaluators develop a list of heuristics that they must address, creating a focus for evaluation (Baker *et al.*, 2002, Kleinig & Witt, 2000; Nielsen, 1995). Depending on the research problem, flexible approach has to be used when deploying this method. Similar to the cognitive walkthrough, usability inspection method must be *expressive*). This method too was used to evaluate the first version of the artefact.

2.3.4.3. Usability Testing

A usability test involves making observations of users completing the goals of an interface (e.g. for a website) while being observed (Nielsen, 1999). Usually sessions last no more than ninety minutes, with up to ten tasks to complete. Participants may be requested to think aloud and comment, and their voice, facial expression and keystrokes may be recorded. Once all participants have completed their tasks, the data is collated and analysed by the researcher or analyst. The intent of the activity is *protective* as it only uses a sample of potential system in a test environment. This activity itself is *inquisitive* where the goal of the activity is to find out the user's experiences in engaging with the activity but the findings can be *directive* or *invigorative* spurring on further work and *informative* in improving the design. This method was also used to evaluate the first version of the artefact and the feedback was provided to the developer.

Table 2.14 - Functions of Usability Testing

Resource	Primary Function	Potential Functions	Unlikely Functions
Usability testing (Activity 21, 22, 23)	Inquisitive	Expressive Directive Invigorative Informative Performative Protective	Adumbrative Ameliorative Integrative
Cognitive Walkthrough (Activity 16)	Inquisitive	Directive Invigorative Informative Protective	Adumbrative Ameliorative Expressive Performative Integrative

2.3.4.4. Co-operative Evaluation

Co-operative evaluation is primarily used to refine user requirements of a system (Monk *et al.*, 1993). Evaluation could be conducted with representative users, or stakeholders of an interface with the designer giving tasks and allowing the user to make mistakes. The activity has the potential to be *inquisitive* through the stakeholder who is responding to the task, *informative* in the findings and *directive* in how the findings guide the design process. The behaviour and comments of the users enable the designer to identify any problems with the prototype. While contextual enquiry enables observation of users in their working environments, the designer with the designer's set tasks controls cooperative evaluation. While co-operative evaluation was not conducted as a separate activity, feedback during co-operative design was used to refine the interface.

Table 2.15 - Functions of Co-operative Evaluation

Resource	Primary Function	Potential Functions	Unlikely Functions
Co-operative evaluation (not used)	Inquisitive	Ameliorative Informative Directive Invigorative Performative	Adumbrative Expressive Integrative Protective

2.3.4.5. Autobiographical Evaluation

Evaluation can also be conducted autobiographically. Sengers (2005) describes an approach based on the designer's personal experience rather than the 'assumed' experience of the participants or users. The overall user-experience can be enriched when the designer is personally involved in the design environment. This can be *directive* in leading the research process, *informative* in bringing own experience to the research and *invigorative* in spurring on the research.

Table 2.16 - Functions of Autobiographical Evaluation

Resource	Primary Function	Potential Functions	Unlikely Functions
Autobiographical evaluation (Not used)	Informative	Directive Inquisitive Invigorative	Adumbrative Ameliorative Expressive Integrative Performative Protective

The researcher did not have sufficient experience in disability care to compare similar or alternative experiences and had to rely on the experience of participants for this research.

2.3.5. Methods for Expressing and Integrating Purpose

Purpose is rarely identified in isolation from another design choice type. Participant observation (Section 2.3.1.1) and Surveys (Section 2.3.1.2) explained how *beneficiaries* could be understood using these methods. The same activities are also capable of identifying the *purpose* based on the roles of *beneficiaries*. Secondary/desk research (Section 2.3.1.3) may inform the study of preliminary purposes.

Purpose can be recorded using Personas (Section 2.3.2.1) and Requirements Specifications (Section 2.3.3.1) when users organise information based on the tasks associated with the purpose of the interface. Worth sketches and worth maps (Section 2.3.3.5) can be used to express *purpose*, and its connections to *beneficiaries* and the envisaged *artefact*.

This thesis starts with an initial purpose as described in Chapter 1 and then records and updates worth sketches as the research progresses. At the end of each iteration, the ADS shift for each design arena is documented.

Section 2.3 explored a range of data elicitation and evaluation methods and the next Section 2.5 makes the first reflective stop to take a snapshot of the realities of a worth focused RtD process, uses the W2C framework, and plans the next phase of the research.

2.4. Summary of Review

When initially exploring research paradigms, it was decided that secondary research was essential to gain a good understanding of any available information for the chosen case study, and to explore potential approaches to working towards a design solution, but at the same time, it was felt that this was insufficient in and of itself, since further design research would be needed to address the research questions. Primary research was thus required to actively acquire data, synthesise a design and evaluate it.

Sufficient prior procedural knowledge (*knowing how*) is required for primary research activities to be carried out effectively, which will produce substantive knowledge. *Knowing how*, or practical knowledge is required to carry out research. For this particular study, naturalistic inquiry was found to be appropriate in understanding the current situation but this method is not suitable to go beyond current practices and provide a solution that does not yet exist.

RtD, as a form of Action Research combining reflection, primary and secondary research activities was chosen, allowing naturalistic inquiry to be included as supporting activity.

This shaped a design research case study focused on an evolving *primary generator* arising from assumptions derived from primary and secondary research activities and reflection that progressively reframed the design problems. This also responded to explicit research questions. Breaks were included in the research process to provide opportunities for reflection. These breaks occurred between groups of activities, and

were used to plan subsequent activities and reframe the research problem and solution as required.

Cockton's (2013b) vocabulary for resource functions were used as a reflective tool and were continuously reviewed in the iterative process to identify the potential function of each of the methods explored in Section 2.3.

- *Adumbrative* (rough outline of an approach's scope)
- *Ameliorative* (an approach's guiding values)
- *Inquisitive* (finds out stuff)
- *Directive* (systematically guides design work)
- *Expressive* (gets stuff down)
- *Informative* (puts stuff in)
- *Performative* (spreads stuff out)
- *Invigorative* (spurs things on)
- *Protective* (keeps things up)
- *Integrative* (pulls stuff together)

The methods used for data collection, collating, presenting, design and evaluation (including ones later rejected after a valid attempt) are listed in Section 2.3 and their anticipated functions are categorised into primary, potential and unlikely. This anticipation is reviewed again in Chapter 10 to analyse the realities of the chosen research approach.

Next, the research process and findings from this chapter are reflected on. Thereafter, while the chosen paradigm and methodology could not state in advance what methods would be used and in what sequence, the phase structure (Figure 2.8) and final emergent thesis structure (Figure 2.9) are presented. Finally, the next phase of activities (reported in Chapter 3) are planned.

2.5. Reflection on Review

This chapter focused on reviewing research paradigms, methodologies and methods that are relevant to engineering and creative design research. This process evolved over time and as new work on research approaches became available.

2.5.1. Sequence of Review

When this research started in 2008, having considered the chosen context, this research started by considering a range of human centred approaches including Contextual Design (Holtzblatt & Jones, 1993), Value Sensitive Design (Lieberman, 2002) and several approaches to designing and evaluating with children. Meta-principles of design (Cockton, 2009) and Socio-Technical Systems were also explored as approaches. They were however, independent of the research paradigms that were explored.

In 2010, Microsoft Research Design Cycle (Microsoft, 2008) was chosen as the appropriate methodology, as the five steps mapped against the plan for the research, as well as research questions that needed responses. The RtD paradigm was embraced in 2011, with which the Microsoft Research Design Cycle was thought to fit well. In 2011 there was an attempt to make steps 3-5 iterative separately once steps 1 and 2 were completed. This was due to more than one activity happening in parallel. In an attempt to find a way to match the evolving research activities and it was decided a parallel methodology was necessary. Subsequently in 2012, the Microsoft Research Design Cycle was discarded. At this point, design arenas and meta-principles were added to track the focus and evaluate findings as the Total Iteration Potential evolved. In 2013 Keller's stalactites inspired the visual tracking of activities that corresponded to design arenas.

It retrospectively considered research paradigms, methodologies and methods were separated and documented. This section reviews the attempted methodologies and other significant methodologies with similar potential. A methodology may be described as collection of activities within a process, where the activities or focus may follow one another or happen concurrently. A sequential methodology is one where a single activity or focus systematically follows another, where these activities are typically organised into phases but activities could also be conducted simultaneously or focus on more than one design arena within a single activity. The methodologies reviewed in this section have been separated largely as sequential and concurrent. In addition, some of these methodologies have also been separated according to the design arenas that they correspond to.

2.5.2. Outcomes of Review

It is important to point out that the literature detailed in Chapter 2 are a selected sample of all the reading undertaken for this research. For example, additional models found in paradigms and methodologies that were not relevant were discarded, as they would not be beneficial. The understanding of research paradigms in Chapter 2 evolved iteratively. The paradigms, methodologies and methods reviewed were not the only ones considered, nor are they the only ones that were used. New methods were developed during the project to support worth-focused research through BIG design.

A range of research paradigms, methodologies and methods have been evaluated in this chapter. However, no potential *artefacts* were envisaged until an initial *primary generator* directed the design. The *purpose* remained focused on developing a solution to enhance the capability of disabled individuals by improving choice and use of AT devices.

This chapter explored methods for identification and expression of *beneficiaries*, *artefact* and *purpose* and their *evaluation*. While Chapter 2 explored mechanisms for moving the research forward, it has not yet identified connections between these design arenas as there is no concrete contextual basis for this. However, there are connections within the *artefact* arena where the suitable paradigm, methodology and the potential activities are identified.

Chapter 2 explored a range of research paradigms, methodologies and methods and demonstrated understanding of a range of research approaches and outlined and defended the approach taken to continue with this study.

In addition, literature on AT (in Chapter 3), value- and worth-centred approaches and some disability models (Chapter 3) were gathered over the first six months of the research. Possible assessment methods (Chapter 3) and further design approaches were explored progressively over the next two years.

From this point onwards, each chapter records how subsequent design research methods were planned and refined based on the progress of previous activities. All approaches identified as those with potential were discussed in this section, but as

design progress was tracked, the function of these approaches changed, and some resources were discarded. The potential functions of these approaches were noted in this section. Realised functions are recorded in Chapters 4-9 at the points of reflection.

The next section explains the overall approach and presents the process that evolved retrospectively.

2.6. Initial Plan and Final Outcome

As already explained in this chapter, a RtD approach employing *creative* design research methods makes it impossible to both predict the entire process at the start of the research and also to pre-plan how each method would be used to achieve the design solution at each point in the study as well as creating new knowledge for design.

The rationale for each of the activities and methods used unfolds across the following chapters. Reflection and opportunistic situations shaped the activities throughout the study. Each phase iterates with reflection on the preceding phase planning for the next phase. This reflective process is shown in Figure 2.8.

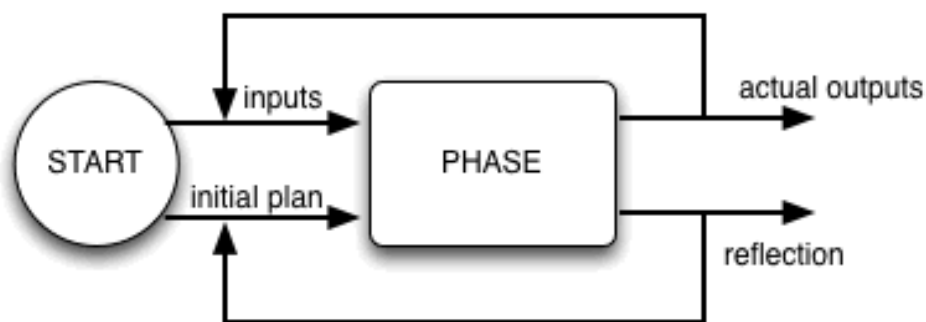


Figure 2.8– Phase Diagram

Reflection, co-evolution of problem and solution spaces and progressive instantiation all combine to produce emergent evolving methodology and later frame the problem and methodology.

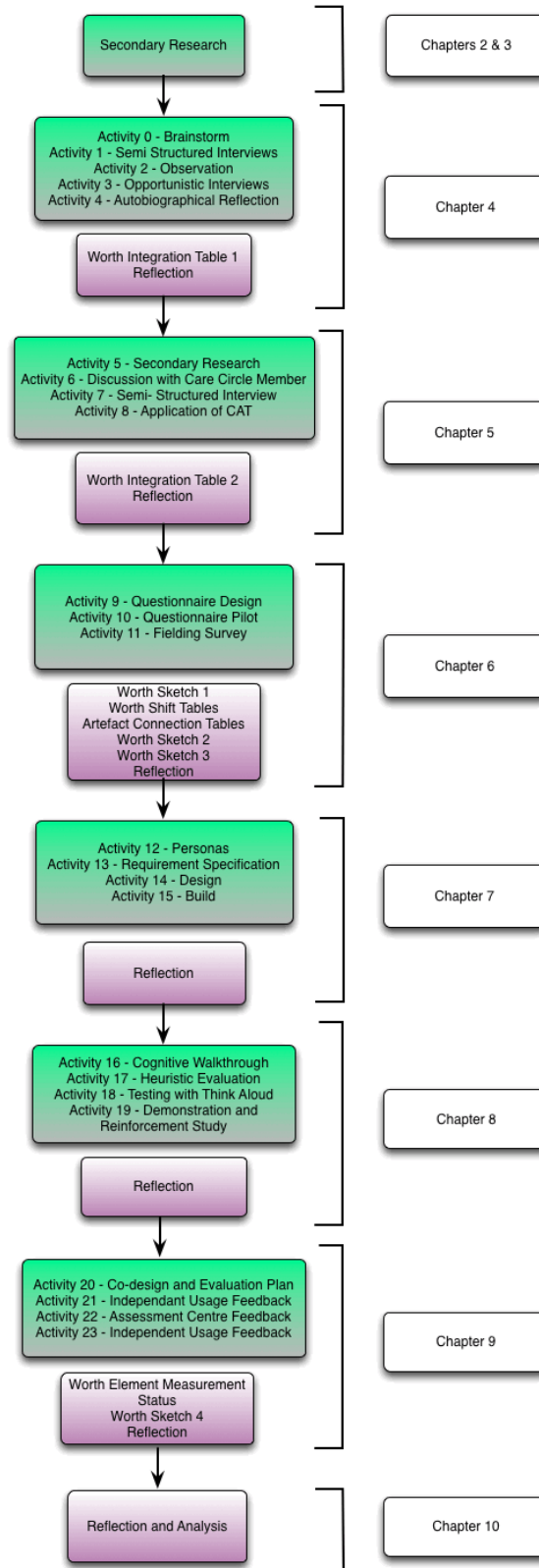


Figure 2.9– Thesis Structure

Figure 2.9 was created once all activities within the thesis were completed. The green rectangles show the activities and the purple rectangles mark reflection at end of iterations.

Some novel design approaches were also introduced in this research process. For example, Section 2.3.3.5. contains explanations of Worth Sketches and Worth Maps. Artefact Connection Table is an original resource used to integrate the *artefact* feature and capabilities under consideration, the related *purpose*, the Potential *beneficiaries* and the Risks of increased costs or adverse consequences. These were also mapped against the activities where these options and possibilities were identified.

Activities 9-10 reported in Chapter 6 are an original approach to designing and piloting questionnaires. During this process, information gathered during interviews and observations over Activities 0-8 was separated into categories of new information to be collected and existing information and assumptions to be confirmed. Questions were then created to address each of these categories and aligned to design arenas.

2.7. Next Chapter

Next, Chapter 3 reports on the literature identified in relation to the case study's complex context including understanding of disability, disability models, existing intervention systems, AT devices and related legal issues. These findings are then followed by a reflection and planning of the subsequent Chapter 4.

Chapter 3 - Contextual Review

The focus of this chapter is to increase the understanding of the design research case study of improving the choice and use of AT devices and thereby improving the circumstances of disabled individuals. Chapter 3 describes the context and focus of this case study. It starts by exploring the model of disability chosen for this research in detail, and unpacks several interpretations of disability based on various models to explore how disability is understood and defined. This is followed by investigation into how disabilities are assessed with a view to providing support systems. The earlier information and activities were based on children as this research started by focusing on children but evolved to be more inclusive of age as a consequence of activities and its findings. Thereafter existing Assistive Technology (AT) are surveyed. This chapter ends with an exploration of legal issues surrounding disability and the activities planned for the next phase of the research.

3.1. Model of Disability: The International Classification of Functioning, Disability and Health (ICF)

Models of disability are used to improve breadth, depth and consistency in understanding disability. As a worth-focused approach that included *beneficiaries*, *evaluation*, *artefact* and *purpose* was chosen, a model of disability that was sufficiently broad to include this approach was also required.

This research used the World Health Organisation's (WHO) (2008) International Classification of Functioning, Disability and Health (ICF) as the model for understanding disability.

The WHO's ICF model defines disability as activity limitations and participation restrictions that result from interactions between impaired body functions and structures, contextual factors and an individual's environmental and personal factors (WHO, 2008, Figure 3.1).

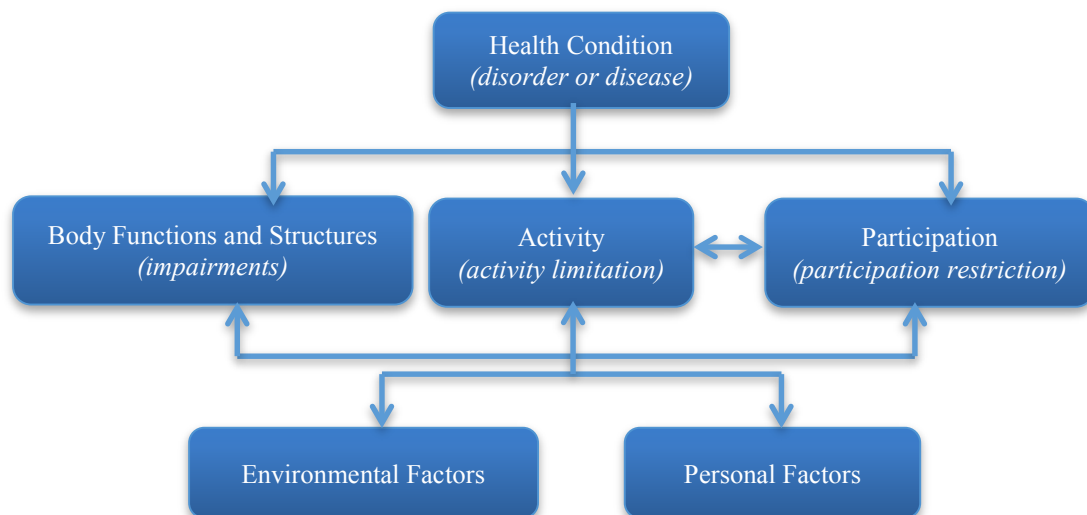


Figure 3.1 - ICF Classifications of Function and Disability

According to the ICF model, “functioning is an umbrella term for *activities* and *participation*, *body functions* and *body structures*” (WHO, 2008, <http://www.who.int/classifications/icf/en/>), each of which are given equal status. Contextual factors refer to the *environment* and *personal* factors of disabled individuals. Disability is thus defined with reference to potentially complex interactions between functioning and contextual factors.

The WHO (2010, <http://p.ideaday.de/104.2/icf/en/index.php>) defines the various components of the ICF model as follows:

- “*Health condition* is an umbrella term for disease, disorder, injury/ trauma and circumstances such as ageing, stress, pregnancy, congenital anomaly, or genetic predisposition.”
- “*Body functions* are physiological functions of body systems, including psychological functions” and “*Body structures* are anatomical parts of the body, such as organs, limbs and their components.” Examples could include loss of limb, stiffness in muscles, and problems with the neurological system;
- “*Activity* is the execution of a task or action by an individual” such as eating and moving;
- “*Participation* is involvement in a life situation” for example a need for activities such as going out to meet friends or using a computer for work;

- “*Environmental factors* make up the physical, social and attitudinal environment in which people live and conduct their lives”. This can include wheelchairs being uncomfortably heavy, the environment not being adapted for wheelchair usage, or a family member willing to provide continuous care.
- “*Personal factors* are the particular background of an individual’s life and living, and comprise features of the individual that are not part of a health condition or health state.” For example, an individual’s age, strength, perseverance and such individualistic traits.

The ICF adopts an approach to modelling disability that combines biological, psychological and social perspectives, which it calls a *biopsychosocial* approach. This *biopsychosocial* approach is more comprehensive than more common *biomedical* approaches, as it looks at participation, environmental factors and personal factors.

The ICF is a multipurpose tool that can be used for providing a comprehensive scientific basis to understand health needs; plan and evaluate interventions; describe functioning profiles in various levels; and improve communication across disciplines and sectors by providing a systematic coding scheme and improved data comparability across different countries, health care systems and health services.

The ICF (WHO, 2008) also provides a checklist for clinicians as a practical tool to elicit and record information on the functioning and disability of individuals. This is a generic document covering all impairment, both physical and cognitive, and spans all ages. The assessment covers impairment of body functions and structures, activity limitations and participation restriction, environmental factors, and other contextual information. In addition there is a health information form, and participation and activity related questions.

What follows is a breakdown of the components that make up the ICF model shown in Figure 3.1.

3.1.1. Body Functions and Structures

Body structures is the first category of *Functioning and Disability* and is generally categorised according to the various organ systems in the body as shown in Figure 3.2.

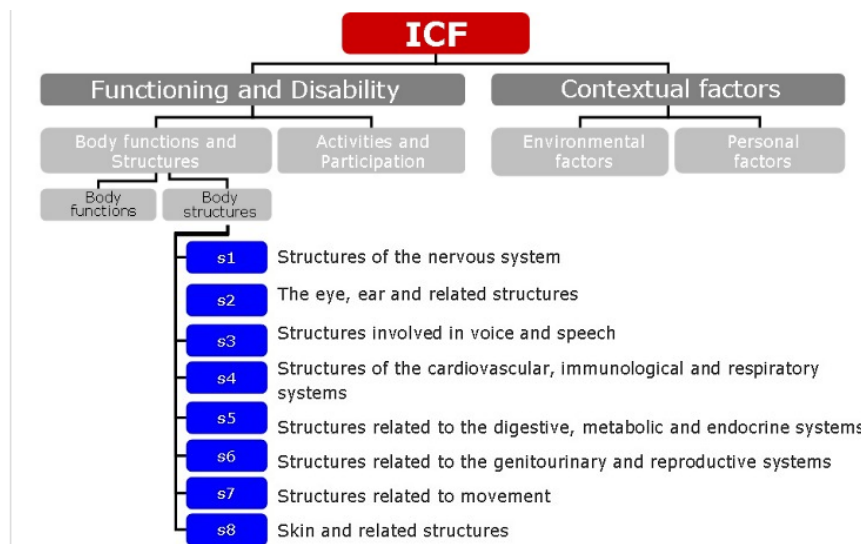


Figure 3.2 – Body Structures

Body functions are be categorised as shown in Figure 3.3 by the ICF.

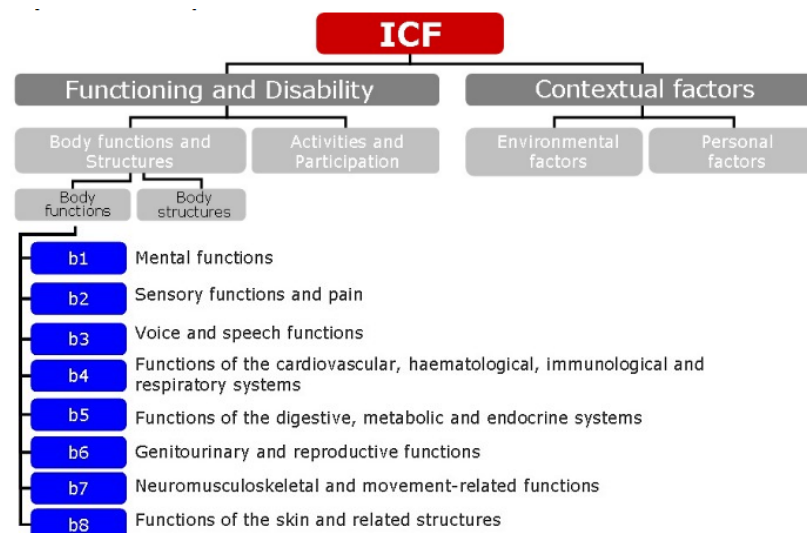


Figure 3.3 – Body Functions

Limitations in these functions and structures could result from developmental disabilities, injury or neurological damage.

Developmental disabilities are a group of chronic impairments that impede the development of one or more abilities, traits, or processes, including physical, cognitive, sensory, and speech skills as opposed to injury that could happen at any time or form during the life of an individual. Both causes may result in limitations in three or more of the following *functions*: self-care, listening and speaking, learning, mobility, self-direction, independent living skills, and economic self-sufficiency (Zisook, 2007).

Motor impairments impede *body functions* that are physical, cognitive, sensory, speech skills, which result in difficulties in activities such as mobility and independent living. The resulting *physical conditions* may be tremor, spasm, restricted range of motion and reduced strength (Keates *et al.*, 2002). Using the ICF model, this situation can be interpreted as body functions and structures that, in conjunction with contextual factors, impede the *activities or participation* of the individual (WHO, 2010).

The medical model views disability as a feature of the person, directly caused by disease, trauma or other health condition as seen above, and requires medical care provided in the form of individual treatment by professionals and in some cases, assistive technology. The ICF extends the medical model into a biopsychosocial model that incorporates environmental and personal factors.

3.1.2. Activities and Participation

Involvement in day-to-day situations, and the activities that need carrying out, differ between individuals. Some may be in employment, while others may be in education and others in full-time care. Participation will be required from peers, families and communities, giving rise to varying demands (see Figure 3.4).

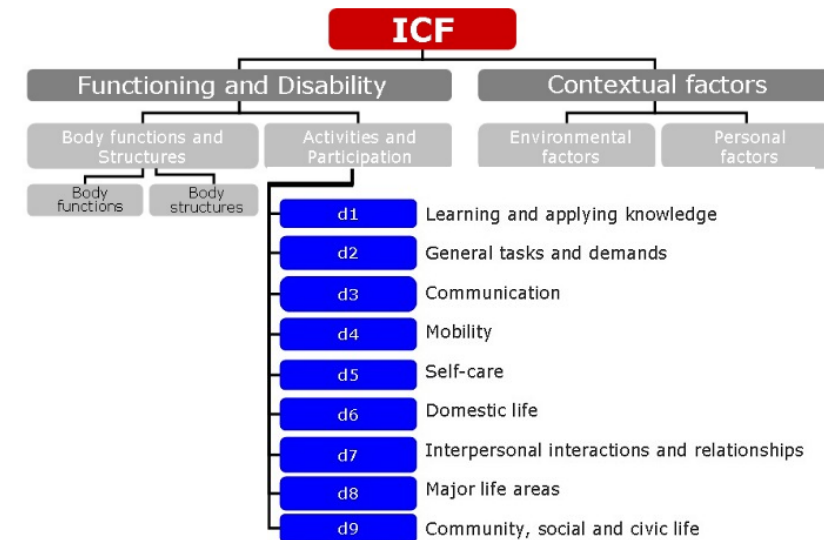


Figure 3.4 – Activities and Participation

Activity limitations are difficulties that an individual may have in carrying out tasks based on the body structures and limited functions. Difficulties faced when involved in day-to-day situations are considered to be participation restrictions (WHO, 2010).

3.1.3. Environmental Factors

The WHO describes environmental factors as “the physical, social and attitudinal environment in which people live and conduct their lives” (WHO, 2010, <http://p.ideaday.de/104.2/icf/en/index.php>).

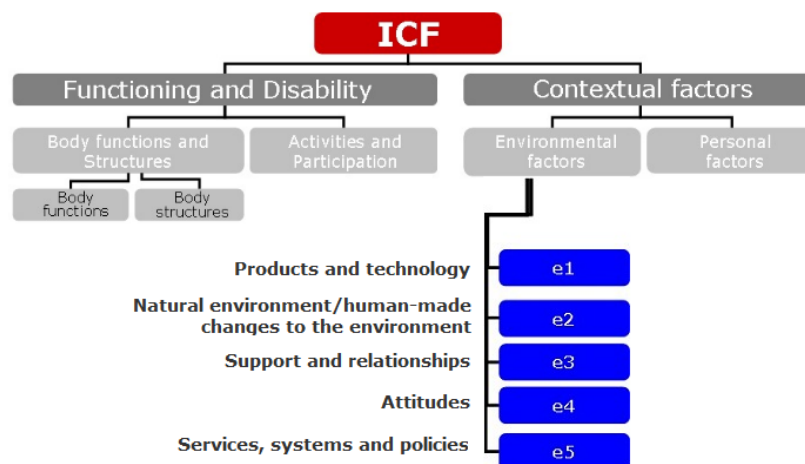


Figure 3.5 – Environmental Factors

The environment is an external factor that may have either a negative or positive influence on the capability of the individual. Figure 3.5 shows various aspects of the environment that may impact an individual.

3.1.3.1. Physical environment

The physical environment includes the layout, comfort and facilities of the place where activities and participation are carried out. The environment may have been built with necessary assistance taken into consideration. Regardless of any health conditions, we have come to depend on certain amenities in our environment, without which we could feel disabled. This may include remote controls, escalators, heating systems, mobile phone or laptops and wheelchairs, special seating and all facilities.

3.1.3.2. Social environment

Social environmental factors, such as family and individuals encountered on a daily basis, influence the capability of disabled individuals. In the UK, an individual's social environment can include immediate family members, extended family members and friends, members of the educational system such as teachers, teaching assistants (TA), Learning Support Assistants (LSA), Special Education Needs Coordinators (SENCO) and those involved medically such as General Practitioners (GP), paediatricians, health visitors, Occupational Therapists (OT), Speech and Language Therapists (SLT), psychologists, and other regular contacts such as peers in either educational or work environments and carers of other disabled individuals. Those who make up the social environment may struggle to work with the technology that a disabled individual has adopted. Problems with obtaining assistance in the physical environment may leave the individual less capable of his or her potential until a suitable solution has been provided.

3.1.3.3. Attitudinal environment

In addition to a supportive physical and social environment, it is important to have a positive and persevering attitude. A notable example is Helen Keller (Keller, 1903) who was both deaf and blind, and for whom, the perseverance of her teacher and mother contributed to the improvement of the development in her communication despite the negative attitudes of her father and brother. Similar examples can be seen

in Anne Sullivan (Davidson & Blickenstaff, 1965), Louis Braille (Davidson & Compare, 1991), Christy Brown (Brown, 2008), and many others who had to fight against the attitudes of those in their environment.

3.1.4. Personal Factors

Personal factors are the attributes of the individual that are not part of the health condition. They include past and present personal experience, lifestyle, education and circumstances. In the case of children with disabilities, their personal experience is limited and to a certain extent can be directed and enhanced by appropriate choices and support. ICF has not classified personal factors yet. However they will influence the individuals' approaches to the circumstances and jointly create the context in collaboration with the environmental factors.

Compared to adults and the aging population, children are less likely to be as influenced by personal factors such as personality, temperament, independence, motivation, past experience, upbringing, demographics and attitudes. These factors are still at a developmental stage and can be changed easily (ACE Centre, 2008). However, adults have a number of personal factors such as past experience, opinions, likes and dislikes. A challenge for children is that they grow both cognitively and physically, and the AT devices selected to meet the biomedical need may fail to develop dynamically together with the child.

The ICF approach to disability centres on activity limitations and participation restrictions that result from interactions between impaired body functions and structures, contextual factors and individual environmental and personal factors. Although ICF defines disability as a condition influenced by the environment and personal factors, from the above discussion it is evident that the emphasis remains on the individual's health and physical condition.

The concepts found in the ICF may have been adopted in some of the assessments used in various organisations, but there is no record of any formal usage of the model. Hersch and Johnson (2008) however, showed how this model could be potentially used (explained further in Section 3.2.5).

3.2. Models used for Design, Choice and Use of Assistive Technology

This section explores further models that can be used to define and analyse disability with a view to providing support for choice and use of AT devices.

3.2.1. Benktzon's Pyramid

Technology users can be categorised as able-bodied or disabled from a biomedical perspective. Benktzon (1993) developed a capability pyramid that places able users as the bottom of the pyramid and the less able at the top (Figure 3.6). The narrower part of the pyramid represents the severely disabled people who are also the minority, whereas the broader base represents the majority of the population who are able-bodied and fully capable. The pyramid is used to understand, evaluate and make design inclusive based on the biomedical condition of the users.

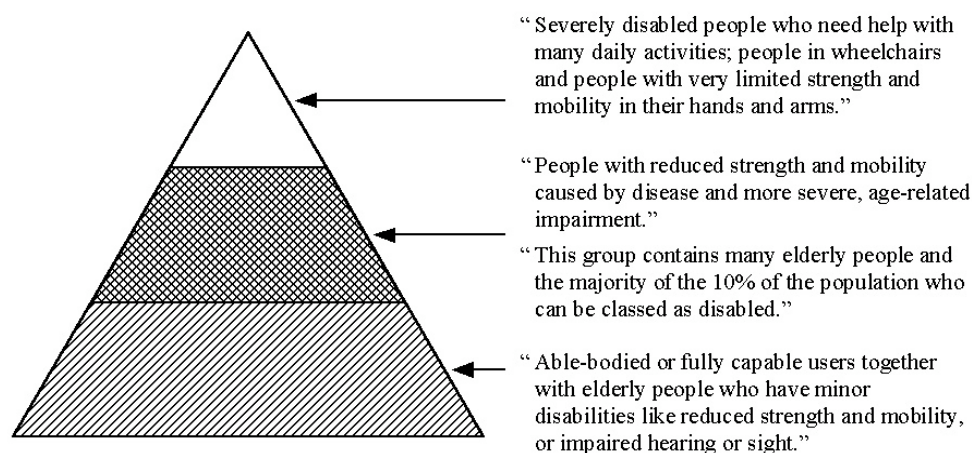


Figure 3.6 – Capability Pyramid (Benktzon, 1993)

A top down approach can be taken where a product or service is designed for the least capable market and thereafter extended towards the mainstream market, or a bottom up approach can be taken where the design begins with the mainstream market and an attempt is made to include the least capable. The three categories use medical diagnosis as the basis of mobility and strength for activities. Therefore, this is a purely biomedical model that is focussed specifically on physical impairment. Cognitive and perceptual impairments are not covered by this model.

3.2.2. Design Cube

Based on the two-dimensional pyramid of Benktzon (1993), the i-design research team developed a relatively advanced capability model (Keates & Clarkson, 2004), Figure 3.7). Their surveys assessing motion, sensory and cognitive capabilities included people aged 16-49, 50-64, 65-74 and 75+. Their model is a three-dimensional design cube (Coleman *et al.*, 2004) that can be used as a guide for the decision-making process for inclusive design.

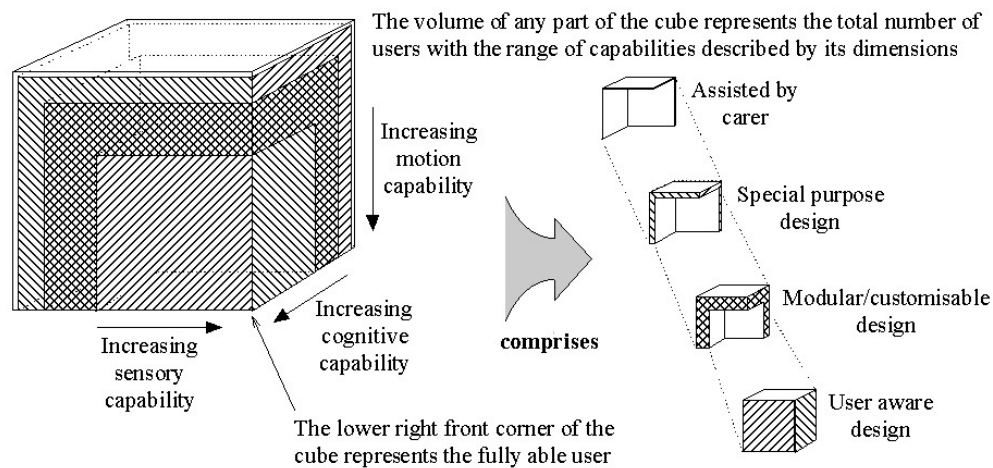


Figure 3.7 – Inclusive Design Cube (Keates & Clarkson, 2004)

The cube represents the whole population where the bottom-front-right corner represents the fully capable user. Capability is measured in the form of motion, cognition and sensory capabilities which, compared to the previous model, consider more than mere physical and motor abilities and extend to cognitive and sensory capabilities. The design process for the users is separated into user aware design, modular/customisable design, special purpose design, and assisted by carer, depending on the position of the user in relation to the back-top-left corner of the cube. This model considers the biological bases of impairment, but fails to take into account the environmental and personal values that contribute towards user capability. Similarly, the context in which the end product might be used and any other environmental factors that impact on capability are not taken into account.

3.2.3. Human Activity and Assistive Technology model (HAAT)

Cook and Hussey (1995) developed the Human Activity and Assistive Technology (HAAT) model that indicates how the *human*, *AT* and *activity* affect each other independently in achieving a set goal, which in turn influence the overall performance of an individual (see Figure 3.8).

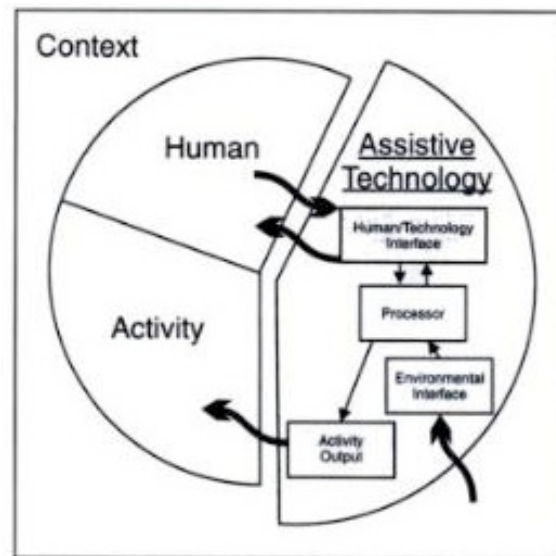


Figure 3.8 - HAAT Model

The *human* factor refers to the skills available to meet the goals, while the context factor defines the constraints on goal achievement, and AT characteristics are defined by the goals, measured skills, and constraints of the context. Here skill refers to the biomedical condition, and the *context* depends on the definition of the set activity, which takes into consideration some environmental factors. Consideration of the innate skills of the *human* to complete these activities refers to the personal factors of the individual.

The HAAT model is the earliest model reviewed (1995) in this thesis as including non-biomedical factors for the first time. It considers both the individual's biological capability and their environment. However, the model is based on a single environment and caters to the needs of the user in order to complete the required activities using technology. This does not meet the need for a model that is applicable to multiple contexts and also personal factors. It also does not include any

consideration of those who make up the care circles of individuals with disabilities or personal factors beyond their capabilities.

3.2.4. Matching Persons and Technology (MPT)

The Matching Persons and Technology (MPT) Model (The Institution for Matching Person & Technology, Inc., 2008) is used to design the life cycle of an Assistive Technology (AT) by identifying the contextual factors that influence the entire process (see Figure 3.9). The process starts with the procurement of the AT device, and thereafter (depending on the duration of the need), measurement of performance and satisfaction are taken into account to decide if the AT device would either be continued or discontinued. Thus, the process results in choice, use and replacement of AT devices.

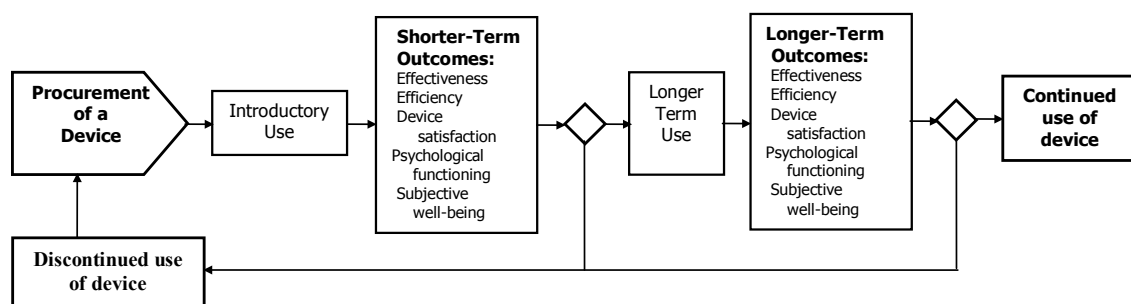


Figure 3.9 - Conceptual Framework for AT Outcomes Assessment, Based on MPT

The MPT model is a dynamic process and was designed for both adults and children. There seems to be limited information on determining the AT needs of the user. Contextual factors include some personal factors, including experience and attitudes to the AT. Environmental factors are unclear, but functioning is taken into consideration by monitoring usage and measuring outcomes.

3.2.5. Comprehensive Assistive Technology (CAT)

Each of the models reviewed in Section 3.1 address some of the components in the ICF model, but there is no functioning model that addresses all components of disability and includes contextual and environmental factors. To meet this void in the application of ICF, HAAT and MPT models, Hersch and Johnson (2008a & b) built

the Comprehensive Assistive Technology (CAT) model, which is based on the ICF conception of disability. This model can be used for:

- identifying gaps in AT provision;
- evaluating existing AT systems;
- supporting design and development of new AT devices; and
- supporting design for all.

The model can be displayed in tree diagrams, labels or tabular formats. The CAT model studies four different domains: *person*, *context*, *activities* and *AT*. The model is laid out in three levels (Figures 3.10 – 3.20).

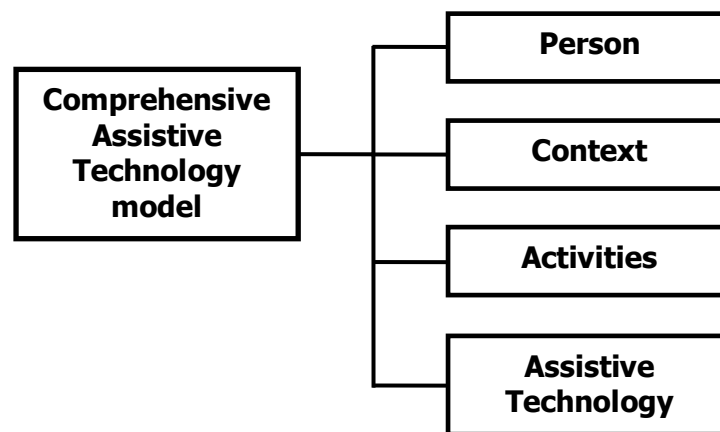


Figure 3.10 - CAT Model Levels 0 & 1 (tree diagram format)

The first component *person* refers to those who will be using the particular AT device or system. The second and third level of this factor shows a clear breakdown of *Person* factors, unlike ICF.

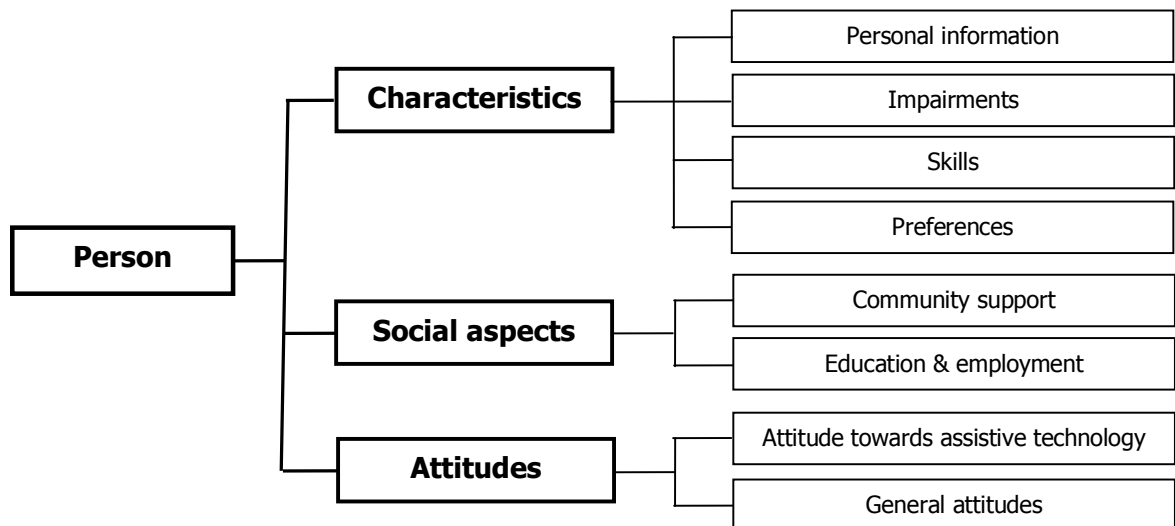


Figure 3.11 - CAT Model Levels 2 & 3 - Person

The model has a third level which includes a further detailed breakdown of *person* factors. The second factor in level one (*context*) is also broken down to two further levels.

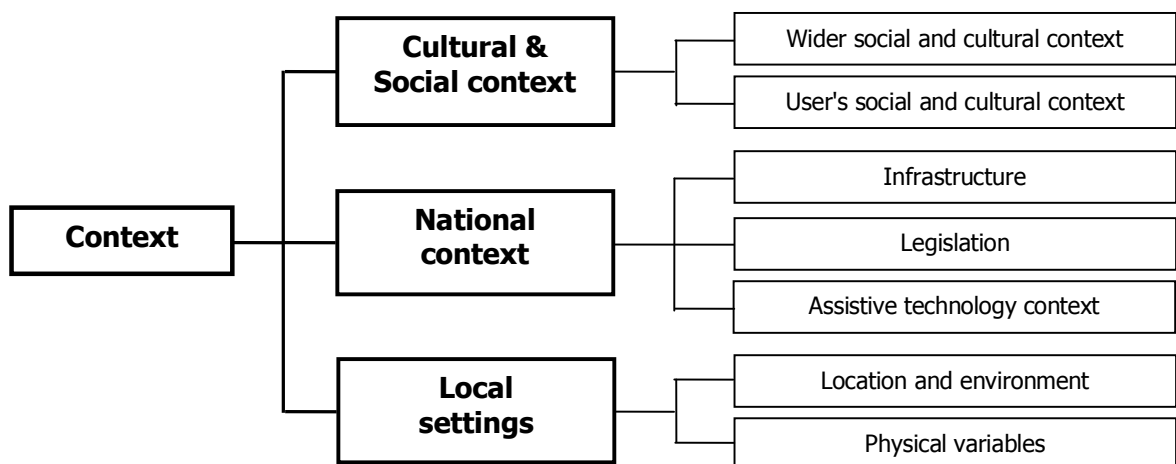


Figure 3.12 - CAT Model Levels 2 & 3 - Context

The next factor *activities* has five sub-components, each of which has several further influential factors making three additional levels as follows (see Figures 3.13 to 3.19).

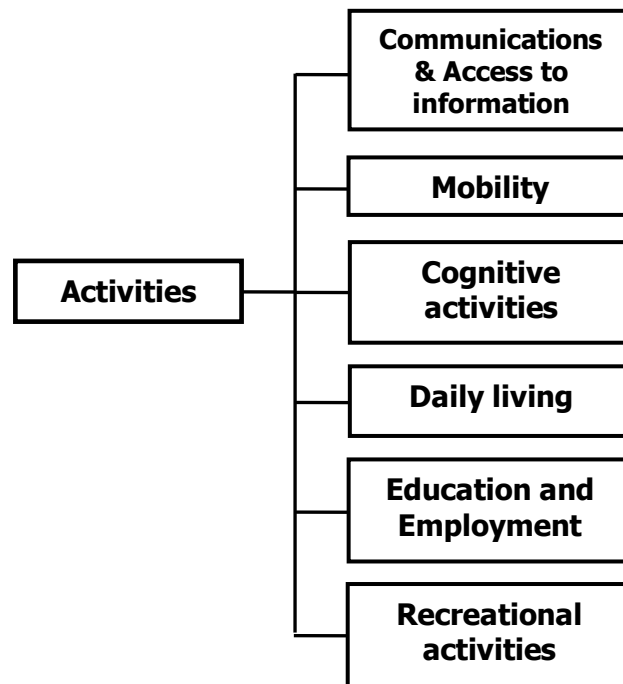


Figure 3.13 - CAT Model Level 2 Activities

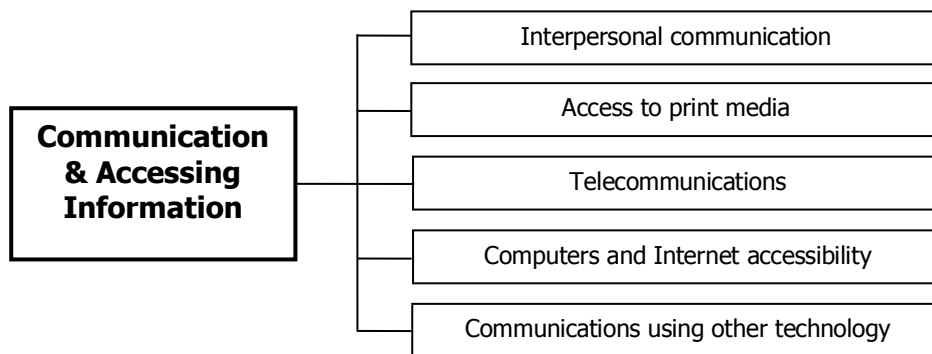


Figure 3.14 - CAT Model Level 3 - Communication and Accessing Information

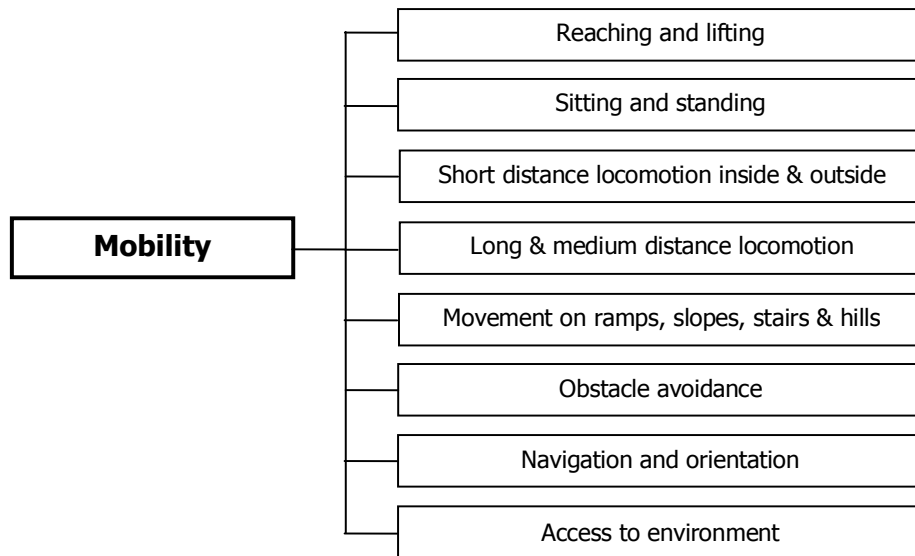


Figure 3.15 - CAT Model Level 3 - Mobility

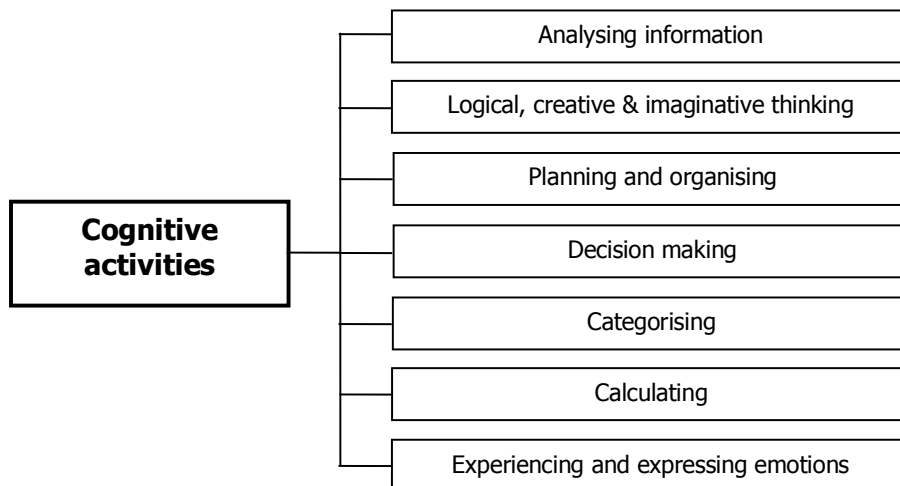


Figure 3.16 - CAT Model Level 3 - Cognitive Activities

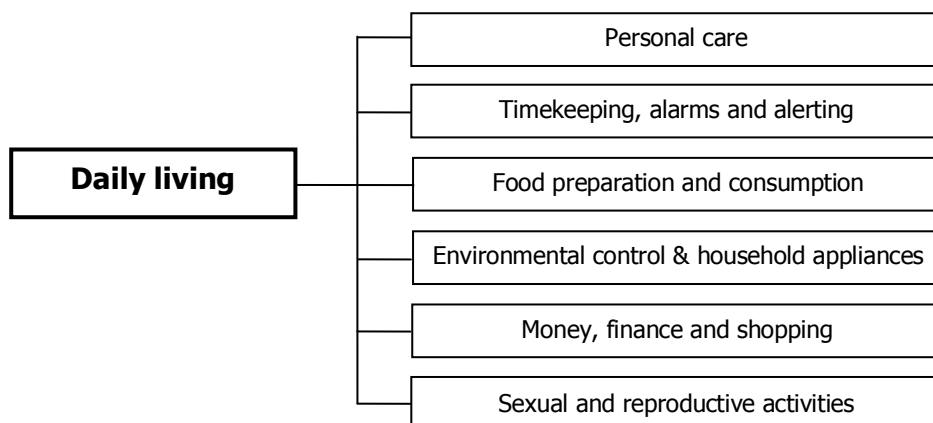


Figure 3.17 - CAT Model Level 3 - Daily Living

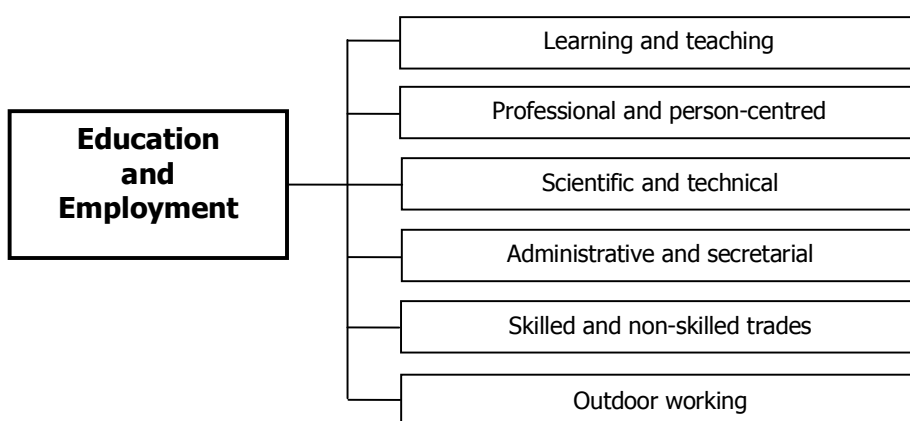


Figure 3.18 - CAT Model Level 3 - Education and Employment

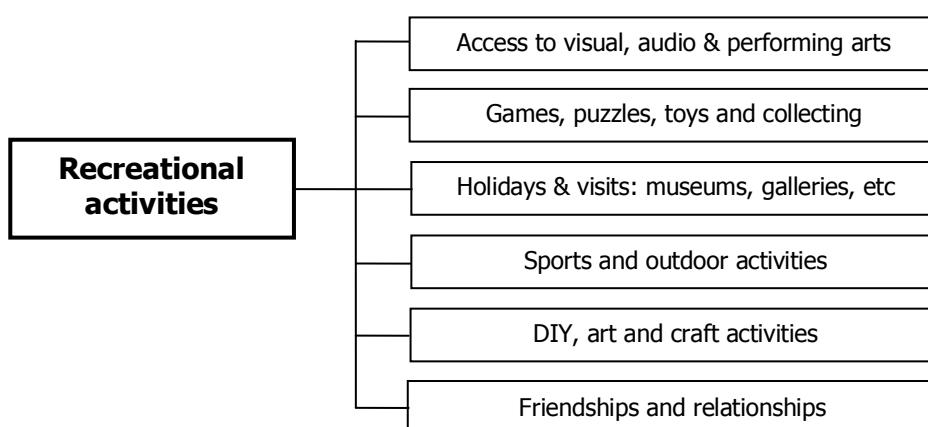


Figure 3.19 - CAT Model Level 3 - Recreational Activities

The final level one factor *assistive technology* has also been broken down into two further levels as shown in Figure 3.20.

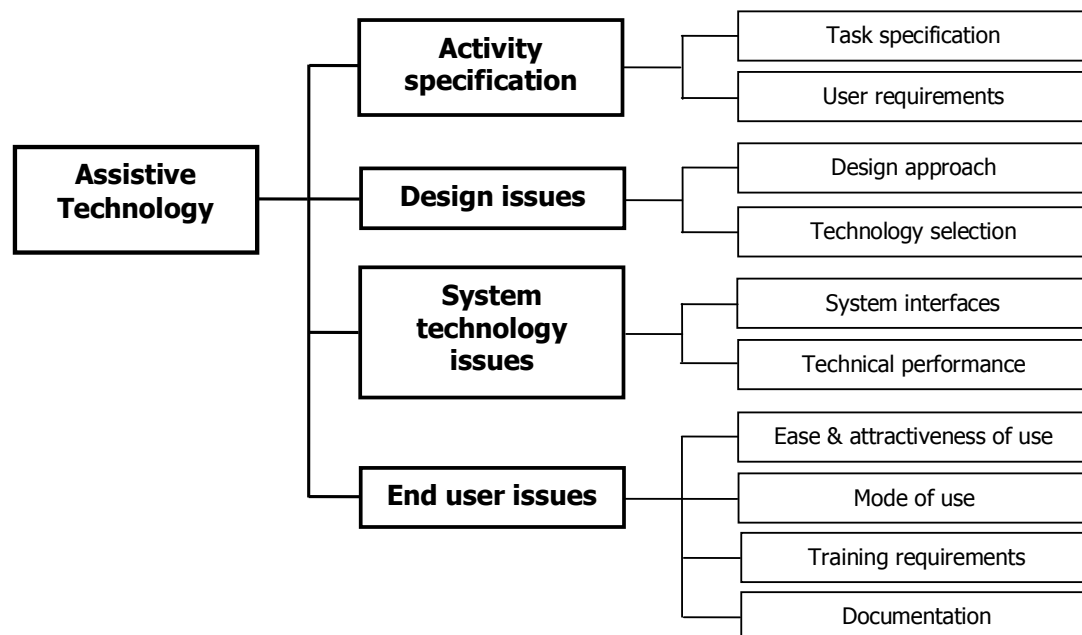


Figure 3.20 - CAT Model Levels 1, 2, 3 - AT

This thesis takes the position that individuals with disabilities are considered to be the primary or default users of AT. The CAT model has been built to address the needs in development, provision, assessment and ongoing support of AT. The CAT model considers all of the ICF's definitions and refines them further to identify what each model component comprises. The CAT model can be used for specific settings and purposes to analyse a specific individual or group of users, the context of usage and location of usage. This model builds further on the ICF model by including personal factors. The CAT model thus seems to be the most comprehensive and the closest to the broad ICF approach to disability.

Hersch and Johnson (2009a & b) analysed existing wheelchair and walking frame usage and ultrasonic cane usage, and identified assistive devices for a deafblind individual with impaired mobility, making their recommendations on the basis of personal factors, contextual factors and location. As demonstrated by Hersch and Johnson (2009a & b), the CAT model can be used easily and as frequently as desired to identify or develop the suitable device. This model could be especially useful in the

case of home-made low-tech devices (manually created vocabulary books, comfortable seating for feeding, etc.) where carers within the family can carry out an assessment and recognise clear needs for the disabled individual who they care for.

Based on level 3 of the CAT model, it also does not appear to be catering to the dynamically developing nature of children, as the model merely takes a static snapshot of physical and cognitive capabilities. Adaptability of technology to children's development of skills and capability is of utmost importance and this could be achieved by designing an effective self-adapting agent. Trewin (2004) proposes that for true accessibility, a device must continuously self-configure its input mechanisms to suit the changing requirements of the current user. A need-based, re-evaluation-based, dynamic model that evaluates a variety of situations is needed to address this.

3.3. Assessment Approaches

Section 3.2 explored various models used for the design, choice and use of AT devices. This section surveys some approaches to how disability is assessed in practice.

Disabilities are assessed and diagnosed differently across the world. As the focus of this study is on practices within the UK, a contextual review was carried out by the researcher of the different types of assessment methods used in the UK. Although the initial focus of this research was on children, this review covers assessment processes for children as well as adults. Individual organisations in the UK were contacted, and both primary and secondary information was collected to understand the existing strategies for disability assessment, choice and use of AT and Augmented Alternative Communication (AAC) devices, four main approaches were identified are presented below.

3.3.1. Special Educational Needs (SEN) Assessment

Special Education Needs (SEN) is a support system provided by the British Government where disability assessments are conducted. All mainstream schools in the UK are required to provide support in the form of Special Education Needs

Coordinator (SENCO) wherever there are students diagnosed with disabilities. The SEN uses a four-question method to identify if a child is categorised as disabled under by Equalities Act 2010. SEN defines disability as “a physical or mental impairment which has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities” (Equalities Act, 2010).

The four questions relate to motor and sensory skills in day-to-day activities, underlying impairment and conditions, if the condition or impairment would last for more than twelve months and if it is more than minor or trivial (TeacherNet, 2006). This is not a formal assessment method, but is used as a guide in schools to identify learning difficulties their students may have. The assessment is made by the teacher or the person responsible for special needs support. This form is completed in consultation with the child’s parent or legal guardian.

The ICF indicates that biomedical factors are considered together with required activities and participation relating to the educational environment. Personal factors need to be considered and the environmental factors need to be extended to include other environments. The SEN assessment is limited to the two to three individuals completing the form, and for the purpose of educational environment only. Although this is not biomedical, this restricted nature of the solution would make a child have difficulty in adjusting to non-educational contexts.

3.3.2. National Health Services (NHS)

The most widely used assessment strategy in the UK is that of the National Health Service (NHS). From the scans obtained during pregnancy to the birth of a child and thereafter during development, the NHS attempts to medically identify any disabilities and thereafter refer them to specialised institutions. The NHS uses a general developmental chart to assess disorders (ACE Centre, 2008). Community paediatricians carry out the developmental assessments based on growth charts and milestones (Bolton, 2001). During these assessments, if any support needs are identified, an AT device or support system may be recommended.

One such assessment system is the *Schedule of Growing Skills* (GL Assessment, 2008a), aimed at 0-5 year olds. This is a form-based assessment completed by

Educational Psychologists, SENCOs, Nursery Teachers, Paediatricians or Health Visitors. Some of the key areas covered in these assessments are: Passive Posture, Active Posture, Locomotor, Manipulative, Visual, Hearing and Language, Speech and Language, Interactive Social and Self-Care Social skills. The *Bruininks-Oseretsky Test of Motor Proficiency* (GL Assessment, 2008b) is used for 4-21 year olds and covers fine manual control, manual co-ordination, fine motor composite, body co-ordination, strength and agility and total motor composite.

Another assessment tool used in the UK is the *Movement Assessment Battery for Children* (Barnet, *et al.*, 2007). This is used to examine manual dexterity, ball skills and balance. *The Hammersmith motor ability score* (Smartnet & PNCR, 2009), and *Miller Assessment for pre-schoolers* (MAP) (Miller, 1988) are also used for similar assessment.

Contrary to children, whose development is more likely to be monitored, adults are expected to approach the NHS should they ever suspect disability, or in the case of accidents and emergencies, and they would be assessed for potential treatment or support that may include AT devices and therapy (ACE Centre, 2008). This is the most common method of assessment in the UK, as it is part of the NHS, and there is national awareness of these assessments and related practices. This assessment is need-specific, and assesses specific manual and cognitive skills.

It is evident, from the forms and procedures used, that therapists make decisions on an AT device to be used based on the biomedical factors, and any information the parent or legal guardian is able to provide. Following diagnosis, Speech and Language Therapists (SLT) or Physiotherapists usually visit the child concerned at home monthly to once every three months (Nyman, 2009). They may make recommendations to how regular physiotherapy or speech therapy could be carried out at home.

Therapists' visits also provide an opportunity for interaction between some members of the family of the individual concerned and medical practitioners. However, environments beyond home, such as school or play groups, together with the required respective activities and participation, need to be considered. Similar to the SEN

assessment, this too is limited to a single environment and requires a broader approach.

3.3.3. National Network of Assessment Centres (NNAC)

The National Network of Assessment Centres (NNAC) (NNAC, 2010, <http://www.nnac.org/>) in UK work together with families to assess and support disabled post-sixteen year old individuals to provide assistance in education, work and personal lives. By the time a child reaches sixteen, personal factors would have developed and children would be capable of making a substantial amount of decisions with regard to their day-to-day life. Post-sixteen students are likely to have been identified earlier and supported via the NHS or other private institutions. It is helpful that post school and non-medical environments are also supported. It is also beneficial that multiple environments are being supported for activities and participation thereby adapting a biopsychosocial approach similar to one demanded by the ICF.

3.3.4. Private Assessment Centres: Case Study

The ACE Centre in Oxford is an example of an independent assistive support evaluating organisation where teams of 3-5 specialists spend 1/2 – 1 day evaluating the needs of a child in order to recommend assistive devices, usage and therapy. Many assessment methods are used to evaluate the type of therapy needed and assistive device solution (ACE Centre, 2007). The ACE Centre also strongly believes that there is no ‘general’ way of assessing ‘special’ children (ACE Centre, 2008a).

The assessment team initially obtains referrals from anyone who may be involved in a care circle made of those from the social environment (as described in Section 3.1.3.2.) including the teacher, SENCO, Information and Communications Technology (ICT) coordinator, SEN, LSA or TA, educational psychologist, paediatrician, SLT, OT and physiotherapist. Background information is obtained from the parents or guardians with regard to the child’s interests, sensory abilities, methods of communications used, reading and writing skills, seating and positioning, mobility, use of toys and control of environments, use of computers and any medical needs. In addition, referrals also provide information on activities relating to education together with any related documents.

The assessment team primarily uses videos taken in the child's familiar environments or observation settings (Bälter *et al.*, 2005) at the centre to analyse the child. During this time, seating and positioning, control of technology, use of computer and communication capabilities are assessed and an action plan put together considering educational, training and support issues.

Reviews are conducted bi-annually, annually or as necessary. This process is expensive, considers a wide range of environments and also involves members of the care circle in the decision making. Biomedical factors and personal factors are taken into account.

This approach to assessment is bio-psycho-social and effective overall, however as a partially state-funded organisation, the assessments are quite expensive and unaffordable for many. More detailed findings from activities conducted at the ACE Centre can be found in Chapters 4 and 5.

3.3.5. Summary

In the UK, when an individual has been identified with special needs, the OT, SLT, SENCO, Education Psychologist and the parent / legal guardian decide on the necessary support needed in the educational or home environment which can include selection of AT. However support of similar quality is not provided in other environments such as restaurants, while visiting relatives and friends or going to parties. This support is limited as individual physical, social and attitudinal environments are different; personal factors are hard to define; and it is challenging to include an extended number of participants in the decision making for suitable AT devices.

Based on the health condition, the day-to-day activities the individual with disabilities needs to carry out with family members and those in education settings, changes may be necessary to the physical environmental to support participation and activities. If the successful support in one environment could be transferred to other environments, the quality of the individual's life could be enhanced significantly. The social and attitudinal environment could be adapted as necessary but it is quite challenging to do this consistently across each environment.

It should also be noted that most special schools have Learning Support Assistants (LSA) or Teaching Assistants (TA) to assist children on a one-to-one basis depending on individual need. The progress and success of the children with special needs gradually becomes heavily reliant on the LSA or TA. A common challenge in such situations is that the assigned LSAs and TAs are changed constantly (ACE Centre, 2009).

The next section explains the type of AT devices that may be recommended as a result of these assessments.

3.4. Assistive Technology (AT)

Assistive Technology (AT) is widely used to reduce the impact of disability. These devices may be low-tech or high-tech and enable users to perform tasks, actions and activities in alternative ways (LaPlante *et al.*, 1992).

Able-bodied users are able to adapt to using many different devices comfortably. Disabled users may face greater difficulties adjusting to different input, output, ergonomic and environment designs each time they use a different AT (for example to communicate) and the device used and its usability depends on the experience of the user (Jordan, 1998).

3.4.1. Motor Impairment and AT

For a motion-impaired user, gaining complete control over control devices can be challenging. For this purpose, they may use a variety of mobility aids, for example mobile keyboards, alternative mice and monitor arms (SpecialNeeds Computer Solutions, 2007), walkers, manual wheelchairs or powered wheelchairs (ABLEDATA, 2007).

For devices that relate to motor impairment, the constant use of arm, wrist and fingers are necessary to have complete control over both low-tech and high-tech devices (such as dedicated software and hardware). Many ergonomic and assistive devices are also currently available in the market as Augmentative and Alternative Communication (AAC), which can be used to add to the more usual methods of voice input and AT, to enable independence for individuals with special needs. This may

also include software-based changes and hardware modifications. Some examples of AT and AAC devices are discussed below.

Where there is limited but some capability in use of limbs, special handles or grips may become necessary to hold small objects and in addition, special bends, curves, handles and grips may also be necessary to improve motor skills (Zisook, 2007). Alternative approaches may also include special keyboards and mice or emulating the functionality of the keyboard and mouse (WebAim, 2007).

However, when there is no control over the arm, alternative communication methods based on other modalities such as speech, mouth, head and brain-controlled interfaces can also be provided.

3.4.2. Sensory and Cognitive Disabilities and AT

Other types of disabilities include sensory impairment that may include invasive and non-invasive corrective eye lenses, hearing aids, sign interpreters, human note takers, screen readers and braille machines. Another type of impairment is cognitive such as Dyslexia, Downs Syndrome, Attention Deficit Hyperactivity Disorder (ADHD), and Autism that would require coping strategies and support software for various activities.

Individuals with cognitive challenges also increasingly use interactive digital devices as support tools (MashableUK, 2013). They could be devices such as those recommended by ACE Centre (2010, <http://acecentre.org.uk/projects>) *Look2Talk*, which is an eye-pointing device or *Sign Language* that are a replacement for speech and communication support tools such as *Special Access to Windows (SAW)* and *Built-in Screen Readers for computers*.

3.4.3. Touch and Gestural Devices

While not always classified as specifically designed for use by those with disabilities, touch-based devices are being used to provide an alternative lighter portable device and to make interaction more intuitive. Touch and gestural interfaces such as Apple's *iPhone*, *iTouch*, *iPad*, and the *Nintendo Wii* incorporate a variety of input, output, data, connectivity and interoperability options. *Microsoft Surface*, a tabletop interface,

enables grabbing and moving data using natural touch and gestures possible (manufactured by Microsoft Corporation). Touch-based e-book readers *Kindle* (by Amazon) and *Nook* (by Barnes and Noble), including their accessible versions, provide further opportunity for users with motor impairment.

Thus, ubiquitous or pervasive computing is brought about by the convergence of media and the physical environment making interactivity more natural and more seamless and also incorporating the social context of usage. There are significant opportunities for social elements with web and mobile applications in multi-touch and multi-user platforms. However there is currently little research attention paid to actual needs arising from disability related conditions.

3.4.4. AT Devices and the ICF

As any other individual, disabled individuals participate in various activities in their home, work and education environments and interact with those in their environments. This will require usage of AT or AAC devices that may be low-tech or high-tech to support them.

As seen in the preceding sub-sections of this chapter, most AT devices are designed to overcome limitations associated with specific body functions or structures which is primarily a *biomedical* approach. They focus on one aspect of disability, rather than looking more widely at *activities, participation, environment* and *personal* factors. Social participation and activities appear to be overlooked except when devices are selected specifically focused on tasks, e.g., dyslexia support in education. However this same support may not be suitable in all social environments. Another reason for failure of *biomedical* approaches is that individuals with similar health conditions may have varying capability, and individuals with different health conditions may have similar capability in carrying out tasks due to environmental and personal factors. This could result with the users having AT devices that are unsuitable for day-to-day tasks, inappropriate for the environment in which they need to be used, and unfit for the individual's personal experience or choice.

Rather than making a *biomedical* decision, if the AT device was chosen strategically, considering both *environmental* and *personal* factors, AT and AAC would increase

functional ability and contribute towards enhancing the overall capability of individuals with disabilities. Therefore the assessment carried out for the choice or use of these devices need to take into consideration the tasks and environments that are part of their lives, that calls for a system that captures the *biomedical* condition along with the *activities* that need to be carried out, *environmental* settings and *personal* factors. This can be achieved by consulting other individuals from the *environments* where individuals with disabilities spend time and also taking into account the *tasks* that need accomplishing.

3.4.5. Summary

A variety of AT tools and aids exist for meeting the needs of motor, sensory and cognitive special needs. A variety of approaches to assessing these needs and recommending support are available across UK. Amongst these methods, it is evident that there is an increasing use of biopsychosocial approaches in various organisations, but these are either quite limited in their coverage of environmental factors, or too expensive.

Another problem could be that family members and professionals involved with disabled individuals may find it challenging to keep up with the rapid changes in the development of technology, resulting in either the disabled individual missing out on improved support or being unable to use devices chosen by others (ACE Centre, 2009).

The next section looks at the available guidelines and legislation that require support for individuals with disabilities.

3.5. Legislation and Guidelines

The WHO (2001) states that disability and handicap arise from the design of inaccessible products and services and not from the users. They further describe how disease, ageing and accident leads to functional impairment, which in turn leads to disability and handicap. The survey of WHO (2001) includes the population aged 1-49 and 75+ but do not include children.

Governments and non-government organisations have developed legislations, guidelines, standards and conventions to encourage inclusive design. Some of the examples are:

- Royal Institute of British Architects (RIBA) Enterprises (2004) sets useful criteria in height and size for accessible design of public telephones, door handles and switches in public places;
- The Centre for Accessible Environments, together with Robert Feeney Associates, has devised inclusive design guidelines for Automated Teller Machines (ATMs) in the UK (2002). Design guides have also been created to cater for wheelchair access and other limitations in dexterity, reaching and stretching, hearing, vision and specific cognition. These guidelines address parallax, lighting, feedback, speech output and interface design specifications (Centre for Accessible Environments & Feeney, 2002);
- A variety of text input and output systems for mobile, tablet and desktop computer devices, which can be customised for disabled users have also been identified (Mackenzie & Tanaka-Ishii, 2007);
- Fain and Folds (2001) listed criteria under which interfaces can be tested for those with limited manual dexterity. These interfaces can also be checked against Section 255, Telecommunications Act 1996 [1193.41 Advisory Guidance], Federal legislation in the US for hardware input, output display; and manipulations. However, this does not apply in the UK;
- All accessibility requirements for developers to design universally accessible web applications could be checked against Section 508 Accessibility Programme, Rehabilitation Act 1993, which is also only in the US (Mueller, 2003).
- Comparable UK legislation does include special measures dealing with children, because the Disability Discrimination Act 1995 was amended in 2005 in the UK to include the rights of children (the relevant provisions can now be found in the UK Equality Act 2010 (c. 15). The Disability Discrimination Act 1995 (as amended) addressed the rights of children and how they could be categorised as disabled (TeacherNet, 2006). It recommends the type of support to be given to children who have been diagnosed with specific disabilities, but no specific

guidelines are provided for this support to be carried out, thus creating a gap in guidelines particularly for educational environments;

- The World Wide Web Consortium also sets numerous accessibility guidelines but once again does not make specific provision for children (W3C, 2008);
- Anthropometrics of the disabled have been defined to assist in developing and updating accessibility guidelines (Bradt Miller & Annis, 1997) focusing on adults over the age of eighteen;
- Children's strength characteristics have been measured for product design safety (Owings *et. al.*, 1975), but are not specific to children with disabilities. It is important to note that the anthropometrics of young children would be very different to adults and constant changes in variables should also be expected.

Key tasks that require assistance are normally undertaken at home, at work or in educational environments. Although universal access-related legislation includes a range of requirements, there are no special measures taken to include children who are in mandatory education and have specific associated needs. Children also tend to learn new technology faster and are rehabilitated faster than adults especially as they learn with no preconceived ideas (ACE Centre, 2008). Their needs also constantly change with their growth and development.

Legal systems in the UK and US emphasise the importance of accessibility support while standards and guides support appropriate adherence. These standards and guides should also be followed contextually where usage is set within an environment where activities are carried out and personal factors, without which even legally compliant environments could be inaccessible.

3.6. Summary of Design Research Findings

The aim of this chapter was to understand the context of the chosen case study in detail and explore existing literature. This chapter explored the chosen model of disability, ICF in detail. It further explored several alternatives to this model. This was followed by approaches to assessing disability within the UK and a survey of AT. This contextual review concluded by looking at the legal landscape of accessibility.

Based on the findings from the literature, the decision was made to focus on the needs of motor-impaired children. However, over the course of the study, it became clear that the age of individuals only defined the needs and not the approach and therefore the research became more inclusive of age. In addition, the need to limit the scope to motor impairment also became irrelevant, as the approach to support would be similar and it also became more inclusive of types of disabilities.

3.7. Reflection

The secondary research in chapter has identified several options for some design arenas. Consideration of *beneficiaries* could be based on existing models of disability, experience of AT solutions, assessment approaches, understandings of the disabled individual and those involved in their care. The identified assessment approaches have gaps in knowledge and practice contributing to poor choice and use of AT devices. This created a design research opportunity to improve the choice and use of AT devices through an ICF based comprehensive approach to disability, which is an *evaluation* tool and also scoped the *artefact*. The preliminary research conducted in this chapter identified a problem that could benefit from design research, and thus indicated options for design *purpose*.

As I was a lecturer for the module Decision Support and Information Systems, at Goldsmiths, University of London, when carrying out the Contextual Review, Decision Support Systems (DSS) was thought to have potential if sufficient information was collated in a database.

The literature surveyed in this chapter is not exhaustive. For example, in an earlier version of this chapter, details of specific AT devices that were identified for a range of motor impairment were removed, because neither a list of biomedical conditions nor a list of AT devices can be exhaustive. These changes made to the contextual literature identified were tracked and can be seen in Appendix C10-Tracking.

3.7.1. Design Arena Progress List

Progress has thus been made in advancing options for design arenas from the findings of the secondary research above. The *Design Arena Progress (DAP) list* below shows

the findings from this chapter. In the subsequent chapters, findings are summarised in this format after each activity with the numbering continuing. These numbers are referred to in subsequent tables used to progress work.

- *Beneficiaries*
 - B1: The review of disability assessment processes showed individuals from family, medical and educational environments involved in all aspects of the ICF model as stakeholders.
- *Purpose*
 - P1: Improve approaches to assessment for AT (improve support for AT choice and use);
 - P2: Identify Motor, Cognitive and Sensory disabilities that can be supported;
- *Artefacts*
 - A1: AT devices should be relevant to a range of biomedical conditions;
 - A2: A design artefact that covers the breadth of the ICF model.
- *Evaluations*
 - E1: A novel support artefact can be evaluated against ICF and other models used for design, choice and use of AT devices;
 - E2: Specifically, the CAT model can be used for evaluating novel support.

3.7.2. Order of Activities

This section explains the sequence of activities. In March 2008, the Contextual Review started as Literature Review with an exploration of biomedical conditions and associated AT. This was followed by models of disability including the ICF, which was explored in further detail in 2009. This literature was revisited in 2011 where further disability assessment approaches were added. In 2013, any literature that did not contribute to the understanding of the current context was either moved to a different chapter or removed and the chapter was renamed to Contextual Review (Appendix C3 – Assistive Technology).

Table 3.1 - Order of Contextual Review Areas

Chapters 3	
March 2008	Survey of AT
June 2008	ICF
August 2008	Biomedical approach; disability models
July 2009	ICF detailed study
April 2011	Further disability assessment methods
May 2011	Initial Care Circle defined
June 2013	Detailed study of AT removed

3.7.3. Realities of Design Arenas

Based on the Contextual Review in this chapter, beneficiaries included disabled individuals and those caring for them included in the assessment methods used by various organisations. The artefact is meant to cover the breadth of the ICF model. In addition, understanding of both *beneficiaries* and *purpose* also inform the potential *artefact*.

Figure 3.21 illustrates the individual design arenas that were identified at a very abstract level, where the existence of a design arena is simply acknowledged. This is called a Most Abstract Design Situation (MADS). No connections between design arenas were recognised at this stage.

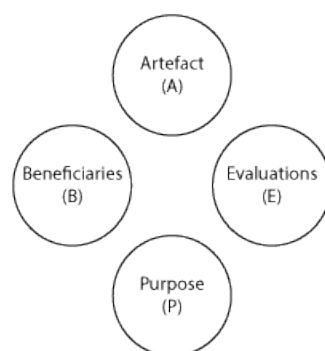


Figure 3.21 – Most Abstract Design Situation (MADS) in Chapter 3

Figure 3.22 shows the relative proportions of findings across these design arenas in this chapter, both as anticipated and as achieved (actual findings). The figure illustrates two Proportional Abstract Design Situation (PADS). Further information on MADS and PADS is given in the guide to the thesis.

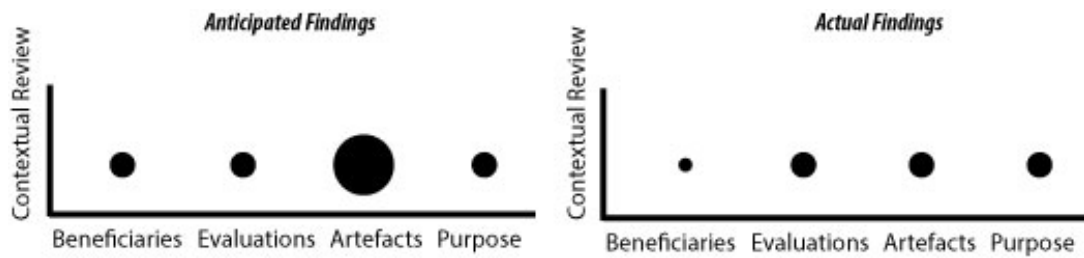


Figure 3.22 – Proportional Abstract Design Situation (PADS) of Chapter 3

The shift in understanding of the scope of the design research as a result of the contextual review is shown in Table 3.2.

Table 3.2 - Shift in understanding of research context

	From	To
<i>Beneficiaries</i>	Initial scope of care circle	Details of specific care circle roles (initially for motor impaired children) and associated challenges
<i>Evaluations</i>	Usability evaluation methods were identified.	ICF/CAT as evaluative approaches were added
<i>Artefact</i>	No specific design intervention in mind	Decision Support System was thought to be a potential solution.
<i>Purpose</i>	Improve support for AT choice and use	unchanged

Tables such as 3.1 above are named as Iteration Shifts from the next Chapter onwards.

The tables and figures introduced in this section are repeated in Chapters 4-9 and are also included in a Guide to this thesis, which further explains what they are and how they are used to aid the reader and provide evidence for the claims made for the research.

3.8. Next Chapter

This contextual review extended the understanding of *beneficiaries*, *evaluation* and *artefact*.

The next chapter is the first design iteration. Based on preliminary understandings, Decision Support System (DSS)s were explored as a potential choice and use solution. This is followed by interviews and observations to assess its viability. In

addition, a reflection on personal experience with a child with disabilities is also documented. The DSS, an *artefact* is anticipated to be the primary generator in the next chapter.

The investigation into a DSS (Activity 0) is expected to provide information on beneficiaries, artefacts and the outcomes of activities that beneficiaries can carry out (purpose). As the investigation is into technical systems, understanding of beneficiaries and artefact is expected to increase more than understanding its purpose. The primary Activities (1, 2, 4) are expected to produce equal amount of information on beneficiaries, artefact and purpose. Activity 3 was opportunistic and was not anticipated at all. Based on the anticipated quantity of findings, a proportional visual was created of the abstraction.

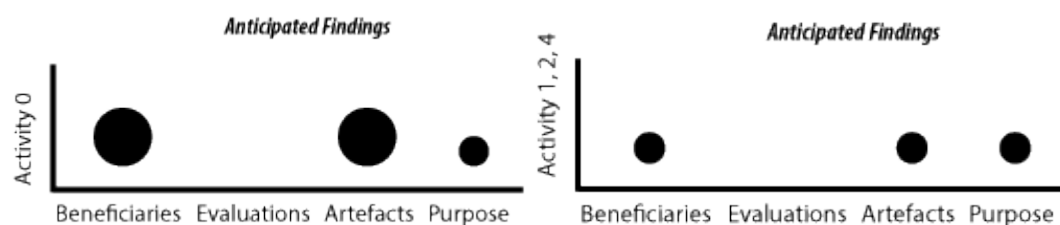


Figure 3.23 - Anticipated Proportional Abstract Design (PADS) Situation for Iteration 1

This anticipation is reviewed within the reflection section of the next iteration to compare against the actual findings. The anticipated shift in design arenas is as seen in Table 3.2.

Table 3.3 - Anticipated Iteration Shift for Chapter 4

	<i>From</i>	<i>To</i>
<i>Beneficiaries</i>	Details of specific care circle roles (initially for motor impaired children) and associated challenges	Additional stakeholders/care circle members identified, with details of their roles and challenges
<i>Evaluations</i>	ICF/CAT as evaluative resources	No progress expected
<i>Artefact</i>	Decision Support System (DSS) as a potential solution	unchanged
<i>Purpose</i>	Improve support for AT choice and use	unchanged

As mentioned in Chapter 1, refer to the ‘Guide to Thesis’ as required from Chapter 4 through to Chapter 9.

Chapter 4 - Iteration 1: Decision Support System as a Possible Artefact

Chapter 1 provided an overview of the research problem. Chapter 2 identified a range of research paradigms, methodologies and activities and selected an overall approach for this research. Chapter 3 discussed the context of the research problem, and identified problems and challenges within the current situation through secondary research. The next step is to realise this first iteration for a possible *artefact*.

Chapter 3 concluded by recognising four potential opportunities for activities to make appropriate design moves in Iteration 1: discussing the envisaged artefact, semi-structured interviews, an observation and reflection on personal experience. However, the observation led to an additional set of opportunistic interviews, which is recorded as an additional activity. This chapter reports on these four activities. These were predominantly *inquisitive* activities that intended to find out more information to *inform* and *direct* the research. The findings may potentially be *invigorative* (spurs things on). A reflection on these activities with reference to sequence and duration of activities, the resulting ADS and resource functions concludes this chapter.

4.1. Research Aims

The aims of the iteration recorded in this chapter are to advance the research as follows:

- Chapter 3 looked at available assessment methods within a disability context. This chapter seeks to understand in detail how special needs are assessed in practice and how AT selections are made, and thus increase understanding of *beneficiaries* and explore the possibility of improving the current situation and support the design of a system.
- Chapter 1 stated that a large number of AT devices remained unused. Chapter 3 looked at a variety of AT support systems such as specialised input devices and multi-touch and multi-user interfaces that could be used to address biomedical needs of the individual with disability. Activities 1-4 in this chapter were *inquisitive* in that they aimed at developing a better

understanding of the current situation, to potentially enable improvement of the situation by being *directive*, *informative* and *invigorative* and assess the suitability of a decision support tool for AT selection, configuration and use.

- This chapter also aims to evaluate and visualise the relationship between *design arenas* and coordinate design options for *beneficiaries*, *evaluations*, *artefacts* and *purpose*.

4.2. Activity 0 - Envisaged Artefact

This activity is numbered ‘0’ as it is the position at this point rather than a proactive activity. At the time this research was conducted, I was a lecturer in, Decision Support Systems, at Goldsmiths, University of London. The idea for a decision support system (DSS – see below) emerged from a combination of the evaluation of ICF described in Chapter 3, the findings gathered at this stage of the research and the subject I was teaching.

DSS is an umbrella term used to describe a computerised system that supports decision-making. DSSs are used to manage rapidly changing economies, operations, competitions and communications with increased accuracy (Turban *et al.*, 2005). The idea for this project was to create a system into which physical or cognitive challenges and activities could be inputted to produce AT device recommendations. For example, to find out what would be suitable for someone who could not use his right arm, a search for appropriate AT might involve the process described in Figure 4.1.

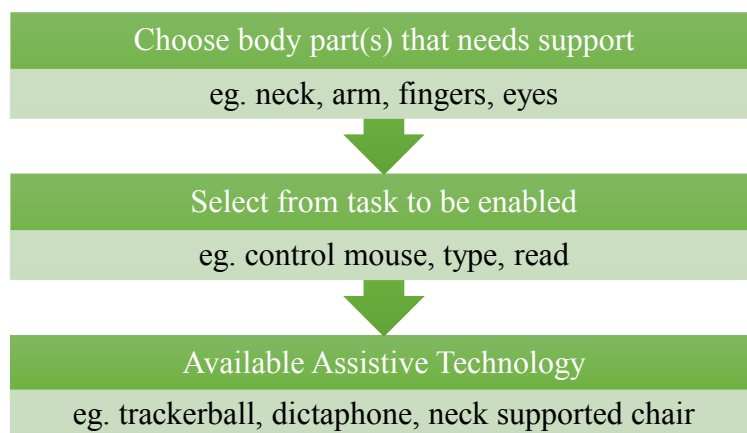


Figure 4.1- Decision Support System

A working DSS would save time and reduce costs and errors related to choice and use of AT. Ideally the system would be based on feedback and existing knowledge and would benefit from a knowledge database derived from professional input.

This activity was not planned but was led by an *artefact* as primary generator. It did not have any intended functions except for providing an idea that might be a potential design solution. The brainstorming of the DSS concept was *inquisitive*; looking at the potential types of DSSs system was *informative* and this information guided the research, which was *directive*. It provided a rough outline of what the *artefact* could be, and was therefore, *adumbrative*. While this activity explored a potential type of *artefact* that may be suitable, it did not identify new *beneficiaries* or *purpose*.

Sections 4.3-4.6 report on Activities 1-4 (i.e. interviews, an observation and an autobiographical study) used to evaluate the feasibility of such a system.

A Design Arena Progress (DAP) list as not created for this activity as this was the position at the beginning of the research rather than a proactive activity. However, an approximate Proportional Abstract Design Situation (PADS) diagram is presented in Section 4.10.2 (Figure 4.5).

4.3. Activity 1 - Semi-Structured Interview

An appointment was made at an assessment centre (henceforth referred to as ‘the Centre’) where children with disabilities are assessed for choice and use of assistive devices. This was the first planned activity. The main purpose of Activity 1 (interview) was to understand choice of AT devices and assessment, with a focus on professional roles in the care of disabled individuals. In relation to resource functions and design arenas, this activity was anticipated to be *inquisitive* and *informative* as it aimed to develop a greater understanding of *artefacts*, *beneficiaries* and *purpose*.

4.3.1. Participants

The assessment centre works with the local special needs schools and the National Health Service (NHS). Children are referred to the Centre for assessment and choice of assistive devices. I met with a Speech and Language Therapist (SLT) and an

Occupational Therapist (OT) for approximately ninety minutes in their work place, ten minutes of which also involved the Publications Officer (PO).

4.3.2. Method

The interviews were semi-structured and qualitative in nature. The questions that guided the discussions were as follows:

1. What, if any, standard scales of measurement are used to assess a specific special need?
2. What are the methods and techniques used, length of typical assessment and specialist equipment and resources required?
3. What criteria guide the recommendation of specific aids or assistive technologies?
4. What is the success rate of recommendations and choices (technical adequacy and emotional satisfaction)?
5. What is the frequency of reviews?
6. Who are the manufacturers of the devices?
7. How configurable are assistive devices?
8. Is there a need to develop the devices or place orders for specialised/customised devices, and how are these needs addressed?
9. Is there any additional advice on further recommended investigation for this research?

All question related to *beneficiaries* while questions 1-3 and 7-8 related to *artefacts* as well. Question 9 was a general one and included all design arenas.

This interview visit was also used to collect assessment forms and literature used at the Centre.

To help respondents prepare, a brief overview of the activity and interview questions were forwarded in advance.

4.3.3. Findings

The interview with the SLT and the OT lasted for approximately ninety minutes. Most of the questions were answered by both of them. The summary of findings from the discussion were as follows:

1. *Measuring of disability:* ‘There are no standard scales of measurement for non-standard users’.
2. *Assessment team:* The assessment team is comprised of an OT, teacher, SLT and at times the Technical Officer. These experts are experienced in both education and health.

Assessment process: The process by which the child is directed towards their assessment centre can vary. Depending on the funding available, this can be through their school, the NHS or via a private referral. Once the relevant sources have contacted the centre, a referral form is sent out to be completed by the contacting party. This form is used to identify how the centre could help the child.

On receipt of the referral form, the teacher, Special Educational Needs Coordinator (SENCO), ICT coordinator, Advisory teacher, Learning Support Assistant (LSA)/Teaching Assistant (TA), Educational Psychologist, paediatrician, SLT, OT, physiotherapist and any other persons listed as involved with the child’s development in the referral form are contacted. These professional members of the child’s care circle are sent individual, detailed forms by the Centre to establish the child’s interests, hearing abilities, vision, face-to face communication, education, seating and positioning, mobility, use of ICT, and any additional information. Guidelines for making a video for the purpose of assessment together with an information form are also sent to the parents/guardian. The video is used to analyse how the child communicates with other children and adults, plays, interacts and has conversations. Using the video, they are also able to assess the motor capabilities. Based on the referrals and the video, an assessment plan is developed and the appointment is arranged for observation.

The observation usually takes up to half a day. The assessment team uses discrete observation to analyse the child, which is done in a professional observation laboratory environment. During this time, seating and positioning, control of technology, use of computer and communication capabilities are assessed and an action plan is put together with any educational, training and support issues.

Based on the findings from all these evaluations, recommendations are made for the child by the SLT.

3. *Criteria guide for assistive devices:* There are no formal tests, measurements or documented support systems for choice and use of assistive devices. The choices are made based on the information forms completed by individuals who care in different capacities during evaluation, and the observation. The base line is language and communication capability. It is not possible to separate learning and communication, thus suitable technology to meet both accessibility and curriculum requirements are recommended.
4. *Success rate of recommendations and choices:* There is a lack of feedback/review and it is not possible to comment on the success or otherwise of the recommendations. It would however be very useful to be able to know how successful their work is.
5. *Review frequency:* The centre has no control over the frequency of reviews. Early diagnosis and intervention increases the opportunity for development. Children returning for review or reassessment depend entirely on the institute they are managed by and the funds at its disposal. The SLT mentioned the case of a four-year-old girl who was first assessed at 15 months and has been reviewed three times since with substantial improvement. She also stated that the younger the child is when first assessed, the more chance there is of improvement. The OT added that the assessment was deliberately loosely structured around task and activity analysis, as it was impossible to have a standard checklist, because no two children are similar in biomedical, environmental and social settings.

6. *The manufacturers of the devices:* The list of suppliers is on the assessment centre's website. The Centre does not directly communicate with manufacturers. One manufacturer is based in the UK, one in Brazil and many others are located in the USA. In the past, some of them have contacted the Centre for feedback and suggestions during product development. The Centre also has some in-house developers.
7. *How configurable are the devices:* All *low tech*, *light tech* and *high tech* devices, that ranged from paper-based to computer-based support, are configurable.
8. *Dealing with demands for specialised/customised devices:* Needs for specific configurations have arisen previously. Most software-based needs are easily met, because most software is PC-based and this would probably take the form of a software plug-in or add-on. Hardware or systems configuration needs also arise, but as the organisation focuses on abilities of individuals rather than their disabilities, they have always found an available device that they would suggest.
9. *Other recommendations:* A list of potential charities and assistive devices were provided. The following literature was collected during the visit:
 - Information on the Centre's approach: The information can be found at: <http://acecentre.org.uk/assessments> (ACE Centre, 2013). This helped to understand the information publicly made available to those who care for disabled.
 - A guide to an upcoming project named 'Speech Bubble'. The project shows a simplified method for providing a range of assistive devices. The completed project can be found at: <http://www.speechbubble.org.uk/>. This is a simple yet rich resource where information on assistive devices is provided.
 - Assessment information and guide pack: this consisted of referral forms for several individuals who care for the disabled individual; information forms for professionals and parents/guardians; assessment plan form; assessment form

and video guidelines. These forms help to understand what kind of information is taken into consideration prior to developing a support plan for the child with impairment.

- Current project related leaflets: this gave a better understanding of other ideas carers may be interested in. They included fundraising and training programmes.

In addition, the main contact at the Centre, the SLT, arranged for a brief meeting (i.e. approximately ten minutes) with the Publications Officer (PO).

The PO was responsible for developing and maintaining their website and the database consisting of assistive devices and suppliers. He was at the time working on the already mentioned Speech Bubble project that was to provide a searchable online guide to technology that can help people with communication disabilities. The website is targeted towards Speech and Language Therapists and parents/guardians who are familiar with the assistive devices. The PO provided me with a copy of the project brief.

The PO mentioned that if I developed a platform that would inform and support a non-specialist in choosing assistive devices, this would complement their own project that manages a database of assistive devices and suppliers. This indicated the benefits of improving decision support for non-professional carers.

4.3.4. Summary

Activity 1 was primarily *inquisitive* and resulted in being *informative* in revealing several potentially relevant insights about identified *beneficiaries* and several options for *artefact* capabilities and design *purpose*. It was *directive* by identifying gaps in data (e.g. look into further types of assessment, further literature on AT devices); *invigorative* in organising further activities and expanding the perceived care circle membership and the potential for the type of *artefact*. The following is the Design Arena Progress (DAP) list of the information gathered from Activity 1 focusing on each design arena and indicating the potential function of the findings:

- *Beneficiaries:*
 - B2: Early diagnosis of disability increases the opportunity for improvement of the child's capability;
 - B3: Manufacturers of AT devices do not communicate directly with the Centre, but are stakeholders;
 - B4: Carers should be supported by information guides and assessment packs that are readily available;
 - B5: There is potential (*invigorative*) for a DSS with a selection model to enhance the existing SpeechBubble project based upon a database of AT. This led to exploring the potential for working on collaborative and complementary research to SpeechBubble;
 - B6: Those who were involved in caring for the child in various capacities were the teacher, Special Educational Needs Coordinator (SENCO), ICT coordinator, Advisory Teacher, Learning Support Assistant (LSA) / Teaching Assistant (TA), educational psychologist, paediatrician, SLT, OT and Physiotherapist. There could be others not mentioned by the Centre (*directive*) and the decision was made to refer to this group as the *care circle*. Further information would need to be gathered to identify additional membership.
- *Artefact:*
 - A3: A choice and use model for a DSS would have to be complex enough to cover the interactions between technology, tasks and environments. It is not simply a question of matching AT to a child and further investigation needs to be done on an appropriate artefact (*directive*);
 - A4: Configuration needs exist and are easily met in the case of software. However meeting configuration needs for hardware need to improve;
 - A5: Information on existing AT devices that supports the choice (eg. what needs of capability or disability this device meets) should be included in the artefact. However the AT list may not be exhaustive and may not meet all required biomedical support;
 - A6: A viable decision support tool would require a choice and use model that could be updated on the basis of feedback about the quality of AT recommendations;

- A7: Assessment information guides and packs that already exist should be included in the artefact;
- A8: Information on carers' interest in their professional practice and support practices, such as fundraising and training programmes, should be included.
- *Purpose:*
 - P3: The DSS or chosen artefact should support what professionals currently do. i.e. diagnose capabilities, produce requirements for AT that suits specific capabilities (purpose) and support design work with developers, keeping beneficiaries in mind;
 - P4: Another purpose of the artefact could be to overcome funding limits as constraints on frequency of assessments or offer more opportunities for assessments at lower costs.
 - P5: There is no standard way to measure non-standard users. This also no published data on the success of choice and usage of AT devices. It would be worthwhile to have a system that collects data. This data would increase the appropriateness of chosen AT devices.

Activity 1 was approached with the idea of developing a choice and use model for a possible DSS. The project SpeechBubble emerged as a possibility that could reach beyond professionally trained carers. In its then current state, the SpeechBubble project enabled users to search for devices by name, feature, software, vocabulary or supplier. Although the Centre normally took a beneficiary focused approach, in the case of the SpeechBubble project they took an artefact centred approach. Supporting choice and use of AT goes beyond finding technology to match disabilities and it should extend to a range of *beneficiaries* in making the correct choice and use.

As stated in B6, it was decided that the term *care circle* would be used from this point on to refer to this group of those involved in varying capacities in the care of the disabled individual.

4.4. Activity 2 - Observations in a Special School Environment

The Centre where Activity 1 was conducted is responsible for some of the assessments for a pre-school for children with severe motor impairment. The Centre put me in touch with a Speech and Language Therapist (SLT) at this school. I made arrangements with the SLT to visit the school and be a silent observer. A few days prior to the visit, I sent an information sheet with the background and aims of the observation to the SLT. The school was open from 9.15am to 3.00pm and permission was granted by the school for me to spend the school day with the class of six four-year-olds.

This observation approach was exploratory, to understand how these children were supported and what their needs were, such as the usage of the chosen AT devices. During this time, I was also able to meet with staff members at the school and conduct brief informal interviews (recorded as Activity 3).

4.4.1. Participants

My main contact in the school was the Speech and Language Therapist (SLT). The SLT guided me to the classroom of six four-year-olds at the beginning of the day, which consisted of three boys and three girls. All six children were held in position by the LSA/TA for their activities and none of the children were in a wheelchair during this time. Though they for the most part had similar biomedical conditions, each of them had varying degrees of mobility and motor skills. Their personal circumstances appeared to have an influence on how much effort the children made in trying to be independent. Each child had his or her own unique way of communicating with others. The children in this activity are referred to as Child R, W, I, C, A, and T.

4.4.2. Method

The day was spent following the normal routine of a class as a silent observer or occasionally (upon request) as a teacher's assistant.

4.4.3. Findings

The children spent the first half of the day with their class teacher and a dedicated LSA/TA for each child. They started the day by singing a 'hello song' and greeted each other, where three children used buttons and switches to sing their part. All the songs that were sung during this session are related to physical movement and coordination e.g., to sit up straight, to keep their head straight, all of which required immense effort. Child T contributed using eye gaze (her personal low-tech device) as she had absolutely no control of her limbs. This AT consisted of a printed library of visual aids from the child's vocabulary that had been gradually built as the child's vocabulary increased (AT were explained in Chapter 3, Section 3.4).

Breathing exercises were carried out in the form of a story. Child W, with muscular problems could not participate. One specific incident worthy of mention involved Child T, who refused to communicate when she realised that she could not keep up with the rest when contributing towards the song. This was due to a delay on the teacher's part in finding the correct pictures for her.

The class of six was then split into two groups of three and taken for a physical exercise session. Children supported each other when one of them found something difficult.

The SLT then worked on their listening skills:

- Children learnt to identify animal sounds and imitate them. Some Children enjoyed making noises while others enjoyed recognising them.
- They exercised their hands by drawing, as all of them had limited hand movements. Children had varying capabilities with their drawing skills linked to the number of fingers that they could use in a controlled manner.
- They went for a break and play using pushchairs, with dolls, mainly to support them whilst they walked. Child T could not go out to play and a new head-switch based game was activated for her by the SLT. She only needed instructions once and followed them accurately. The distance between her head and the two switches was not ideal and at times she could not reach them. She found it hard to

keep her head steady and hence produced unintentional clicks. The SLT was working with the Centre to help Child T with this. Child T had some frustrations in using her AT device. She had 'yes' and 'no' bands on her wrists so that if any of us needed confirmation, she would either look at the wrist or lift it slightly.

This pre-school follows the National Curriculum for children in this age group and provides support to assist them with their motor skills and communication through their transition to mainstream schools and if necessary, after they have progressed to mainstream schools.

I noticed that two of the children had useful 'communication guides', that had been developed for each child which they carried with them in their wheelchair for anyone who wanted to communicate with them. This booklet briefly explained how to communicate with the child and what devices, if any, had to be used.

The children went for a swimming lesson and then to lunch. They had varying difficulties or challenges from being tube fed to being unable use their hands. They were given support to try and feed themselves as they could not control their hands/arms steadily. This time was also used to encourage children to use their hands and speech by for example, putting their favourite food on the weaker side and encouraging the child to ask for things pointed at by the weaker hand.

Following lunch, two of the children remained for speech therapy with the SLT. Child I had reportedly improved from no speech to sentences within 18 months. She was described as very persevering and enthusiastic.

The next task was to stick fur onto a huge troll. Most children enjoyed the activity. Children who could not use their hands were given paint to splash and play. Child W was careful not to dirty his hands or apron and did not participate much. The SLT explained that not getting their hands dirty was generally a symptom of eating disorders or difficulties.

Child T could not participate at all and she typed a report about her day using her head switch device, symbols and small words. This was followed by story time to which children were encouraged to use AT devices to respond and also shout answers. After this, their parents collected the children to go home.

Activity 2 showed that the care circle of the children was wider than had been initially assumed: their classmates, teachers, teaching assistants and therapists support the children. This also showed that the environment and personal circumstances had a strong influence on the child's capability to be independent and perform despite his or her diagnosed disability.

4.4.4. Summary

Activity 2 was primarily *inquisitive*; the findings produced by the activity were *informative*, *invigorative* and *directive* regarding *beneficiaries* and *artefacts*. Design decisions that emerged from these activities included:

- *Beneficiaries:*
 - B7: The care circle needs to include peers, teaching assistants, therapists and parents of other children. Thus, the scope of the care circle extended beyond what was understood in Activity 1;
 - B8: Children need to be understood as individuals and not by their clinical diagnosis. This should include information about other influential personal and environmental factors;
 - B9: Characteristics of children are understood by their response to tasks;
- *Artefacts:*
 - A9: The artefact should record the extent of knowledge available about the disabled individual and the devices used to support them. It should cater to different needs of the care circle members.
 - A10: AT devices may be needed continuously across different environments (*directive*). An approach to design, choice and use of AT needs that would work for all beneficiaries should be identified;
 - A11: Weaker capabilities and faculties of the children should be identified and focused on to encourage usage for development. The potential *artefact* should record for example exercises that facilitate this at home (*directive*);
 - A12: Communication guides or manuals have been / should be produced for each child and can be beneficial to anyone outside of the care circle who tries to communicate with disabled individual. A potential for this should be included in the design of the artefact (*directive*). This will help

with improving the communication between the disabled individual and anyone who is not familiar with communicating with them;

- A13: AT devices are used for specific tasks in school such as identifying animal sounds, drawing and break-time play. It is uncertain how the details of these tasks could be shared but a way to share these tasks with the care circle needs to be incorporated within the artefact (*invigorative*). This will be beneficial for continuous and consistent use of these devices by members of the care circle.

Activity 2 was *informed* by findings from Activity 1, *invigorated* by opportunities to extend the potential of the *artefact* and gave *direction* to create an *artefact* that meets the needs based on *information* about care circle established in Activity 1. Activity 2 revealed the extent of the educational professionals' activities and their relationship to their working environment.

A choice and use model would have to be complex enough to cover the interactions between technology, multiple environments and associated tasks. It is not simply a question of matching AT to a child. In addition, the choice of AT should ideally reflect the most up-to-date diagnosis. Building this into the DSS would be quite challenging.

Based on the findings from the observation in Activity 2, the following questions arose.

1. What is the protocol for selecting AT devices?
2. For what purposes, and to what extent, is the chosen AT used?
3. What type of training is necessary to use devices?
4. Is it possible to configure the AT devices to suit needs of environment and individuals?
5. Are there any existing problems with the chosen AT devices?
6. Does rehabilitation require change in devices due to progress?
7. Is there a need for further AT devices?
8. How effective are the ATs used? Are there any devices that have been recommended, but do not work?
9. What is the reaction of children to using AT?

An attempt was made to find responses to these questions after the school observation when an opportunity for an additional activity arose.

4.5. Activity 3 – Opportunistic Interviews

After the Activity 2 observations, I was able to meet briefly with some other members of staff in the school for brief discussions. This extension of Activity 2 attempted to find further *information* on choice and use of AT devices and sought responses to the questions via an informal interview approach.

4.5.1. Participants

The following members of staff introduced themselves and discussed the research focus with me.

- Specialist Team Manager, Physical Disability Service
- Consultant Advisory Teacher
- Speech and Language Therapist (SLT, key contact)
- Speech and Language Therapist (SLT 2)

4.5.2. Method

Opportunistic discussions were carried out as and when I came across the above members of staff. *Specialist Team Manager, Physical Disability Service*: He introduced himself and voluntarily provided a good historical overview of the school.

He also suggested three other professionals in the building who it might be useful for me to talk to; I was able to speak to two of them, the *Consultant Advisory Teacher (CAT)* and Speech and Language Therapist 2 (SLT 2)

Finally, this activity was closed by way of a discussion with my main contact, Speech and Language Therapist (SLT).

4.5.3. Findings

Consultant Advisory Teacher (CAT): She explained that they had divided the work into communication support and motor skills support. Children with motor skill

impairment are part of mainstream schools and those with communication support are usually in special schools. While this showed there may be differences in care circle structures, the difference between the capabilities of children was more important. This further proved that an approach based on the ICF model that considers factors beyond the biomedical, such as personal circumstances, should be adopted. The CAT worked with motor skills. The major part of her work was in mainstream schools.

The process for children supported in choice and use of AT is as follows:

- a) Schools refer students to the CAT for any communication problem. The problems could range from illegible handwriting to cognitive difficulties.
- b) Hardware needs are assessed either by the CAT or referred to a team of assessors, e.g. does the student need a spell checker, special mouse, specialised laptop?
- c) If necessary, based on the hardware choice, the software is selected by the CAT, e.g. predictive typing.
- d) The hardware and software are purchased by SEN/ICT
- e) The Teaching Assistant (TA) is trained to assist the child in their school.
- f) The CAT or assigned assessor continues to review the progress every six months (the disability statement indicates annual review).
- g) Support is amended or removed gradually based on improvement.

Speech and Language Therapist 2 (SLT 2): SLT2 worked with special schools and addressed communication needs. She was fairly new to the job and had a very different approach. She mentioned that she used numerous conference notes as assessment guides, but used her own method, which combined several discrete methods for assessment.

She looked at (1) Devices that were based on need and preferences (2) Access for devices: hardware, portability and software and (3) Vocabulary development requirements based on cognitive abilities such as words and symbols used.

I went back to my main contact, the SLT to debrief. She mentioned that the school did not group children by their medical diagnosis, Child W being a good example as although his medical condition was different to other children in his class, his

capabilities and needs were similar. Besides, looking at diagnoses also contradicted the focus on capabilities. The assessment team simply looked for capabilities such as Child T's eyes and Child W's best finger and looked for ways of using them. The SLT was willing to test any model if they could use it over a period of time. However, she warned that SLTs and other staff members in the school may also be novice users of AT.

Questions arising from Activity 2 in Section 4.4.4 were answered in Activity 3 as follows.

- *Questions 1: What is the protocol for selecting AT devices? Question 3: What type of training is necessary to use devices?*

The Consultant Advisory Teacher (CAT) or assessment team conduct an assessment and recommend an AT device, which is then purchased by the ICT or SEN. Thereafter, a TA is trained to support the user on a regular basis.

- *Question 2: For what purposes and to what extent is the chosen AT used?*

Assessment of the AT device takes place with the school/learning environment in focus. The usage is not restricted in any way.

- *Questions 9: What is the reaction to using AT? Question 6: Does rehabilitation require change in devices due to progress? Question 4: Are you able to configure the AT devices? Question 8: How effective are the ATs used?*

Depending on the age and gender of the child, they may react differently to using an AT device, e.g., adolescent boys may find usage of technical devices impressive or embarrassing. AT support is reviewed every six months, and the AT is either changed or removed gradually. Effectiveness would be reflected in gradual removal of AT and reduced support.

- *Question 5: Are there any existing problems with the AT? Question 7: Is there a need for further AT devices? Question 8: Are there any devices that have been recommended but do not work?*

Any new AT that would help children is always useful. There are challenges with the AT devices as children outgrow them quickly and there are difficulties in getting technical support when newer versions are released. There are some unused devices in the cupboard that were thought to be useful but abandoned due to complexity of usage as well.

Activity 3 confirmed the findings of Activity 2 and showed that there was no standard process for assessment and it was unique and differed according to schools, care circle members, environments and available resources. The care circles involved in each child's case were also different.

4.5.4. Summary

Activity 3 was *inquisitive*, that resulted in being *informative* building on findings from Activity 2 to add further findings about *evaluation*, *beneficiaries* and *artefacts*.

- *Beneficiaries:*
 - B10: Care circle membership should be expanded to include other professional roles within the school. The roles of CAT, SEN/ICT and TA should be introduced or expanded depending on their responsibilities (*directive*);
 - B11: The needs of mainstream schools and special schools may be different;
 - B12: SLTs and possibly other members of the care circles may be novice users of technology.
- *Evaluation*
 - E3: While this activity did not directly evaluate any *artefacts*, there was willingness by the participants of the activity to evaluate any outcomes from this research (*invigorative*). This provided an incentive and assurance to get back to the school with the potential artefact.
- *Artefacts:*
 - A14: There is a need for AT device updates or replacement to be regularly made available and carried out (*directive*);
 - A15: Children were not grouped according to medical diagnosis but according to capabilities. It is not beneficial grouping them in any way

other than by their capabilities, which is in line with the ICF model (*directive*). This provides a capability focused approach. The artefact therefore should respond to capabilities instead of medical diagnoses;

- A16: The artefact should facilitate disability assessments despite any differences in the process used and across any assessment centre or school (*directive*);
- A17: Support should be provided for both communication and motor skills (*directive*);
- A18: the artefact should consider preferences, access and requirements of disabled individual;
- A19: Assessment methods and practices should differ not only based on the child but also on the SLT.

Over the course of this activity, the understanding of care circles increased further. The requirements of the artefact extended to multiple environments and tasks carried out there thereby increasing beneficiaries and artefact features.

Similar to Activities 1 and 2, Activity 3 was *inquisitive* and resulted in being *informative* in revealing several potentially complex insights about identified beneficiaries and several options for artefact capabilities. Participants' willingness to evaluate any potential artefact was *invigorative*. Findings about the artefact requirements suggested that the system had to be used in multiple environments and by multiple users and would potentially need to be customisable for the adaptation of different types of organisations. This was *directive* in the realisation that a DSS may not be sufficient to meet the envisaged needs of the research problem.

4.6. Activity 4 – Reflection on Personal Experiences

Child D was a friend's daughter. I knew Child D from birth when she was diagnosed with Cerebral Palsy and was quadriplegic. I was in continuous contact with the family and extended care circle, being a friend of the family. This section is a reflection on the experience with a child with severe motor impairment over the period of two years and eight months.

4.6.1. Participants

Activity 4 attempted to understand in detail the structure and intercommunications of a specific Care Circle. The description of the child is as follows:

Profile: Child D, Age: 2 years 8 months

Medical conditions: born 24 weeks; Cerebral Palsy affecting all four limbs as a result of Oxygen being cut off during one of several operations.

Motor control: Moves both arms randomly at objects she wants and continues until those communicating with her get it right. Stops hand movement and smiles with approval.

Communication: Non-verbal, to grab attention, she could breathe quite loud. Communicated with family and relief school but not her speech therapist.

4.6.2. Method

I had the opportunity to spend time with Child D in multiple environments including her home, my home, church and hospital. Child D's mother also provided updates on any unusual incidents by phone.

4.6.3. Findings

Child D's mother was asked who she thought the people in Child D's *care circle* were. Based on her response, Figure 4.2 shows the care circle of Child D, showing the family, education and medical roles.

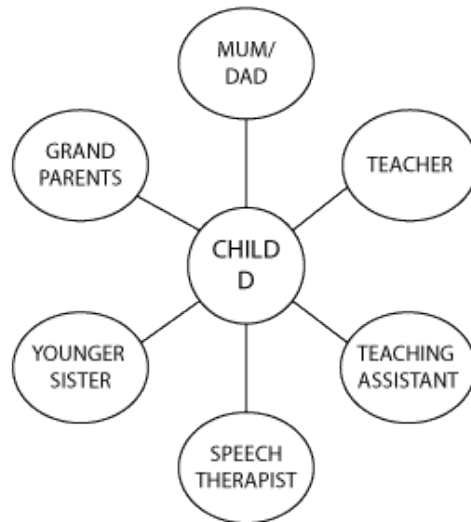


Figure 4.2 - Child D's Initial Care Circle Model

Spending more time with Child D's family, it became clear that there were other members who were involved in the care circle who the mother had not thought of as obvious decision makers or carers. Further, the various members of the care circle had contact of differing frequency with the child. The care circle diagram was further refined by identifying additional members of the care circle and noting their frequency of contact (Figure 4.3). This enabled reflection on the frequency and quality of care circle interactions that exposed a range of issues for their non-professional members.

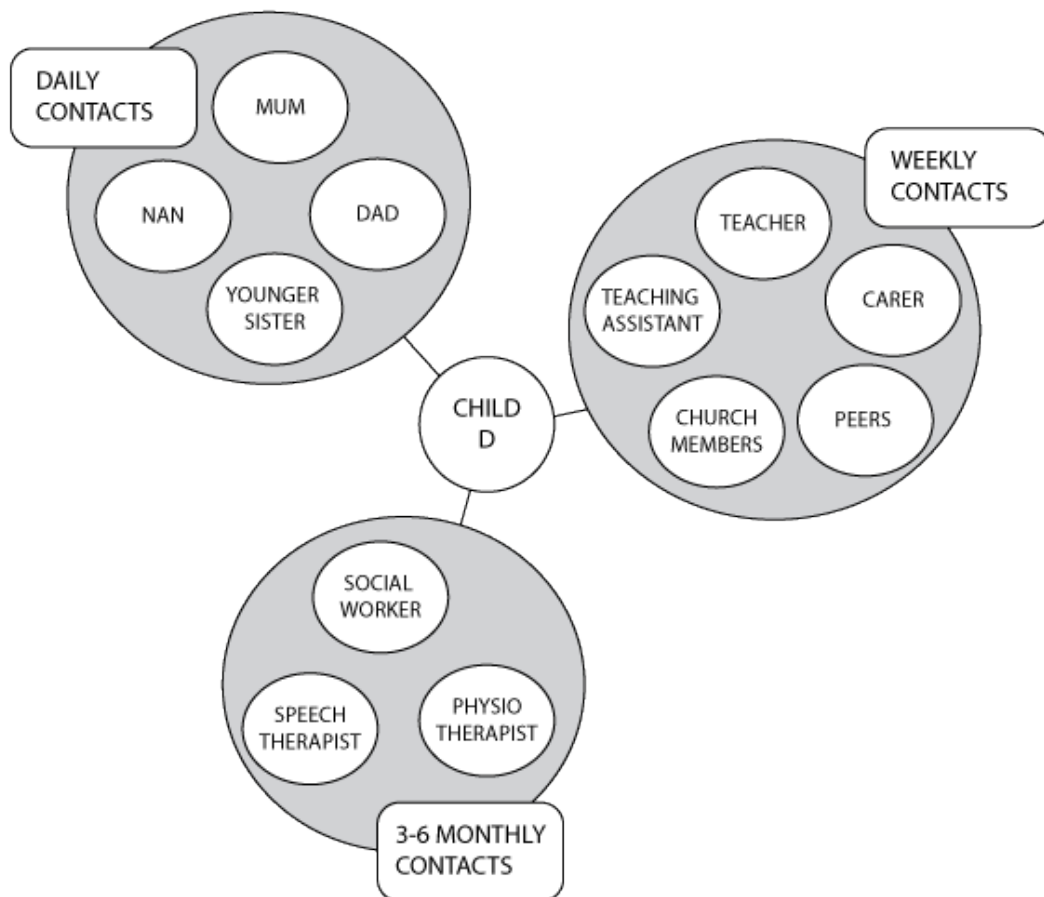


Figure 4.3 - Extended Model of Care Circle

Figure 4.3 shows the frequency of contact of various care circle members. There was no correlation found between the frequency of contact and the decision making on AT choice and use. This may have been due to parents relying on experts to make decisions even if the experts would see the child only every 3-6 months.

During Child D's early days of diagnosis, the family members struggled to get details on appropriate support from the hospital or the local authority. The assessment for a diagnosis and support plan took almost two years, which also delayed timely support. Child D's mother informed me that she continuously sought sources of reliable information on appropriate schools, assistive devices and any other available support. It was always difficult to get a timely or reliable response. This was significant in having a system that provided reliable information while any delays in the NHS formal processes took place and earlier intervention could be provided.

Child D was able to progressively establish how she chose to communicate with people. Her mother mentioned that during one of the social worker's bi-annual visits to monitor her child's food intake, Child D refused to eat since she was unhappy being watched by a stranger and had her eyes closed, making the visit of the social worker fruitless. Child D's mother mentioned that an ideal situation would be, if there was a shared record system that held information about the child's capabilities, needs, care circle membership, their practices, and informal assessments, she could video the child in her familiar environment (probably using her laptop webcam) and posted a link, it would have been more effective and saved a lot of time and effort.

Only those from Child D's daily contacts and weekly contacts knew how to communicate with her. Most of the monthly contacts found it almost impossible, unless they knew exactly how to communicate with her.

Activity 4 identified the need for a reliable and consistent system that makes all the necessary literature available to its users, facilitate a support group and be available and accessible to everyone in the care circle. Thus, the need for a repository that holds reliable and helpful guidance and information became necessary. This also showed the importance of making available details of how each child communicates to those who have contact with the child regardless of the frequency of contact. It was clear the artefact would need to be more than a decision support system that works as a choice and use model. While a DSS can be used for choice and use of AT devices, in this case the lack of knowledge in obtaining funding by family members, lack of awareness of available NHS systems and processes at their disposal and assessment approaches available may end up with AT devices that are in good condition being abandoned. As a result, a new form of artefact was envisaged as an information repository that supports care circles with social networking capabilities, from before diagnosis and onto continuous support.

Activities 1-3 looked at children and care circles already engaging in choice and use of AT devices. Activity 4 looked at a case study where the immediate care circle was not aware of assessments, NHS systems, funding or the extent of their effective care circle. Some basic needs of care circles in this situation were identified from this activity.

4.6.4. Summary

Activity 4 produced *informative* outcomes for *beneficiaries*, *artefacts* and *purpose* and *directive* outcomes for required *artefact* features and capabilities.

- *Beneficiaries:*
 - B13: The design artefact should assist inexperienced, non-professional carers (such as parents);
 - B14: Should include social workers;
 - B15: It should include additional care circle members.
- *Artefacts:*
 - A20: Should not impose standard care circle. This must be custom built (*directive*);
 - A21: It should communicate understanding of the disabled individual's capabilities, needs, care circle membership and practices, including informal assessment by legal guardians;
 - A22: Provide initial support together with facilitation of assessment for disability intervention in a familiar environment;
 - A23: It should provide information on methods of communication to the care circle;
 - A24: It should provide information on a wide range of assessment agencies, as well as on devices and assessment and funding procedures.
- *Purpose:*
 - P6: It should make visits of professionals (e.g. social workers) more effective.

4.7. Mobility Models

All four activities showed that information flow is an important component for effective communication within a care circle.

Mobility models, based on the concept of consolidating flow models (Beyer & Holtzblatt, 1998), were developed for at this point of the study to reveal the travels of care circle members between the various environments. They were complemented by

corresponding tables that revealed the frequency of contact with, responsibility for, and method of communication with the disabled individual.

The nodes in these models referred to places and organisations and not roles (Holtzblatt, *et al.*, 2005), hence the use of the term mobility models, rather than flow models. The mobility models mapped different environments and identified communication paths that revealed information breakdowns, which is implicit in responsibilities of roles shown by arcs. These models can be found in Appendix C4 Mobility Models.

While the identification and visualisation of these information flows were *expressive* and helped focus on increasing communication and reducing travel between care circle members, this did not provide an opportunity for extending any findings by further *inquisitive* activities. As it could not lead to further *informative or directive* insights, it did not add value to the overall research, have impact beyond themselves, or produce return on effort and were therefore discarded.

4.8. Worth Integration Table 1

The findings and outcomes from the four activities revealed new needs (purpose) that a design solution would have to meet, the type of artefact that might be suitable, and potential features of that artefact. The Worth Integration Table 4.1 makes connections between artefact, purpose and potential beneficiaries, in order to highlight benefits, costs or risks/aversions, thus enabling the identification of worth (Section 2.2.1.3). Where no obvious connections between design arenas were available, the gap was marked as ‘to be confirmed’. Based on the possible artefact features, a risks column was also created for each artefact feature. This shows integration of findings from Activities 1-4 and shows how they can be taken forward. This was an innovative resource developed by the researcher and is a methodological contribution to design (research) knowledge.

This table simplified requirements and matched artefacts with purposes. Ten artefact feature groups matching 10 purposes are identified in Table 4.1 and there are six risks, four of which relate to incorrect information and the remainder to incorrect assessment and usage.

Table 4.1 - Worth Integration Table 1

<i>Artefact feature and capability group under consideration</i>	<i>Related Purpose (Benefits)</i>	<i>Potential Beneficiaries</i>	<i>Risks of increased costs or adverse consequences (Purpose)</i>	<i>Activity No. (Source)</i>
Provide peer supports about AT amongst care circle members (A5, A17)	Sharing experience and recommendations (P3, P4, P5)	Child & care circle (B1-B16)	None	2, 3
Information about new AT devices (A12)	Increase awareness of new and improved AT (P5)	Child & care circle (B1-B16)	None	0, 2
Support for AT for choice and use across different environments (A1-A3, A6, A10, A15)	Support communication in personal and educational environments (P3)	Child & care circle (B1-B16)	Biomedical approach/holistic approach not taken (P1)	Chapter 3, Activities 0, 1, 2
Provide reliable technical support to care circle members on chosen AT (A4, A5, A7, A9)	To support care circle using the device with the child and reduce frustration of child (P1, P2)	Child & care circle (B1-B16)	Incorrect information	1
Membership and participation of teachers and teaching assistant, able to add new care circle members at any time (A16, 20)	To be finalised (better integration with educational needs)	Child & care circle (B1-B2, B4-B16)	None	1, 2, 3
Online Assessment and reviews (A7, 16, 18, 19, 22, 21)	Access to more participants in the assessments (P4, P6)	Child (B1-2)	Incorrect assessment	1, 4

<i>Artefact</i> feature and capability group under consideration	Related <i>Purpose</i> (Benefits)	Potential <i>Beneficiaries</i>	Risks of increased costs or adverse consequences (<i>Purpose</i>)	Activity No. (Source)
Discussion or forum (A4)	To be finalised (Support for customising AT device, or environment, or use)	Child & care circle (B1-B16)	Incorrect information	1, 3
Share expert advice and resource files e.g. assessment, fund raising forms (A5, A8, 24)	Reduces repetition of advice from experts, spreads knowledge of good practice. (P4)	Entire care circle (B4)	Incorrect information	1
Individual information on disability, communication guide, calendar, events (A8, A9, A13, 23)	To be finalised (Manage information relating to child's communication, progress, reviews, assessments, etc.)	Child & care circle (B2-B16)	Incorrect information	1, 2, 4
Asynchronous and Synchronous modes of communication (A6, A10)	To be finalised (Reviews can be informal, frequent and up to date)	Care circle (B2, B4-B16)	None	1, 3
Songs, and therapy related exercises (A11, 14)	To be finalised (More regular practices rather than waiting for the turn in school)	Child and care circle (B1-B16)	Incorrect usage	2

4.9. Summary of Iteration 1

The aims of this iteration were to develop a more detailed understanding of the assessment of special needs in practice, to increase understanding of the members of care circles, and to evaluate the potential for a DSS for the configuration, choice and use of AT.

The focus of Activity 0 was to envisage a possible DSS as a primary generator for the design research that would support the choice and use of assistive devices via an interactive decision support tool. This was based on the researcher's experience of teaching Decision Support Systems over a semester. The purpose of Activity 1 was to understand the assessment of special needs and choice of AT devices, with a focus on professional roles in care circle. The focus of Activity 2 and Activity 3 was an exploratory observation and opportunistic interview to better understand how young children with disabilities were supported and what their needs were. Activity 4 extended the exploratory focus of Activity 2 and Activity 3 via a reflection on personal contact with a child with severe motor impairment over two years and eight months.

4.10. Reflection on Iteration 1

The research paradigm chosen was Research through Design (RtD) with reflective stops. This iteration included primary research with naturalistic inquiry. Over Activities 1-4, design arenas were addressed in parallel and enabled iteration of design arenas in parallel, rather than being sequential. This process is now reviewed in detail.

4.10.1. Order of Activities 0-4

While this chapter identifies the resource functions used during activities following from Chapter 2 and Chapter 3, in reality, Activities 1, 2 and 3 happened (over two consecutive days in January 2008) at the very beginning of the research even before the disability models in Chapter 2 were explored. Activity 4 was recorded a year on in January 2009 (Table 4.2). Detailed contemporaneous records were kept and analysed later as activities for the purposes of this chapter as the research continued to make progress. This shows that while there were some activities that happened in sequence,

some were in parallel or were analysed later. Reflection in this sense could happen long after the initial design activity. This is a form of research *into* design that extends prior research *through* design.

Table 4.2 - Order of Activities

Chapter 4: Activities 0-4	
January 2008	Activity 1: 28th January 2008
January 2008	Activities 2 and 3: 29th January 2008
January 2009	Activity 4: Experiential study documentation
August 2012	Activity 0: Envisaged Artefact

It is also significant that some of these activities triggered (*inquisitive*) exploration of further literature on disability and models, assessment methods and influenced identifying design approaches such as worth sketches and mobility models, based on which further additions were made to Chapters 2 and 3. While the teaching of DSS took place over academic years 2009-2010 and 2010-2011, Activity 0, which provided the initial primary generator (Darke, 1979) of DSS that drove this iteration, was retrospectively documented only in August 2012. The concept of care circle diagrams evolved from literature on locales (Giddens, 1984), and mobility models from flow models (Holtzblatt *et al.*, 2005). Both were re-usable resources, but did not contribute directly towards subsequent design decisions and can be found in Appendix C4.

Chapter 4 started with Activity 0, where a choice and use model implemented within a Decision Support System was envisaged for the benefit of family members of children with disabilities. This provided an initial outline for the potential artefact and was *adumbrative*. This was followed by four activities where each activity was incrementally *inquisitive* of *beneficiaries*, *evaluation*, *purpose* and *artefacts*. Activity 1 one lasted for 90 minutes; Activity 2 for six hours; Activity 3 for approximately one hour and Activity 4 during the course of 2 years and 8 months over regular telephone calls and personal visits to the hospital and the child's home. The time allocated for each of the activities also did not necessarily correlate to the amount of findings from each one. For example Activity 3 was the shortest but provided the most number of DAP list items.

4.10.2. Scope of Iteration 1

At the most abstract level, Activities 1-4 were led by the primary generator *artefact*, and coordinated options for *beneficiaries* and *purpose* (Figure 4.4). The circles show the design arenas that were present, with the orange circle being the primary generator.

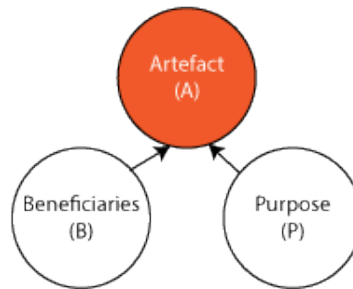


Figure 4.4 – Most Abstract Design Situation (MADS) of Chapter 4

The outcomes of a design research activity did not always conform to expectations. For example, Activity 0 was meant to identify an artefact that would help beneficiaries identify the appropriate AT device to complete specific tasks by searching for AT by medical condition, body parts and task. Therefore, *beneficiaries* and *purpose* were included for better understanding of biomedical conditions and *artefact* for the solution. However, the findings from Activity 0 neither increased understanding of beneficiaries nor purpose. Instead, it would simply filter existing information and enabled identification of AT devices for body functions.

Figures 4.5-4.8 show how the anticipated and actual Proportional Abstract Design Situation (PADS) findings were different.

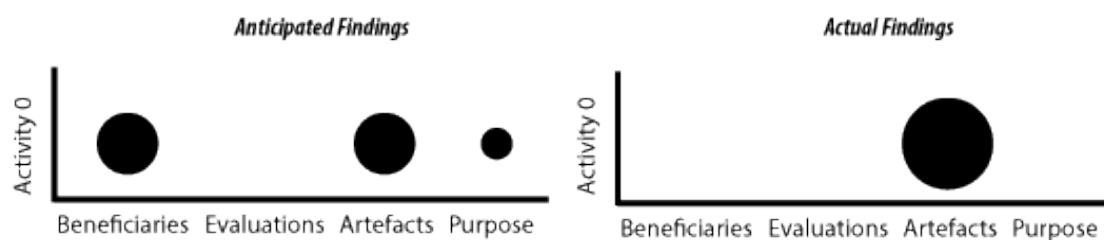


Figure 4.5 - Proportional Abstract Design Situation (PADS) of Activity 0

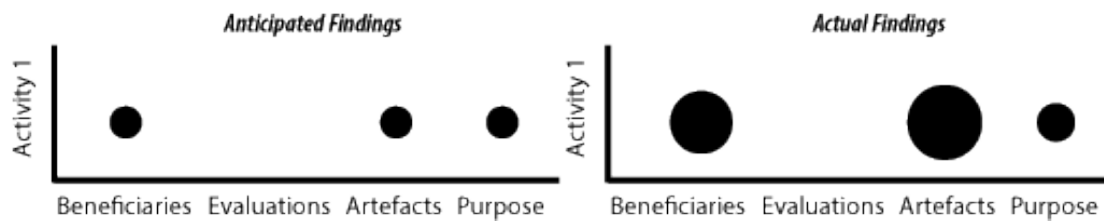


Figure 4.6 - Proportional Abstract Design Situation (PADS) of Activity 1

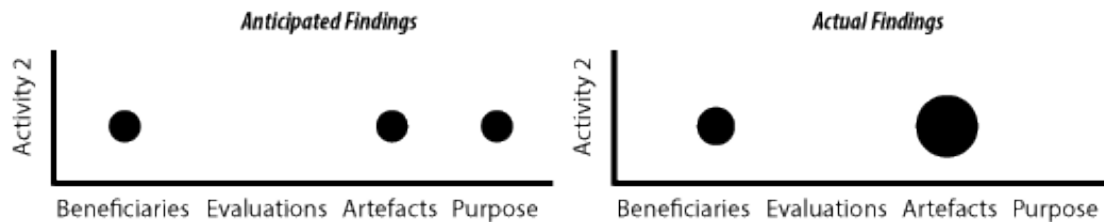


Figure 4.7 - Proportional Abstract Design Situation (PADS) of Activity 2

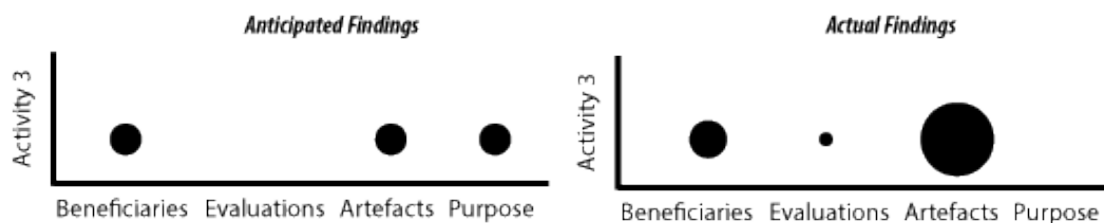


Figure 4.8 - Proportional Abstract Design Situation (PADS) of Activity 3

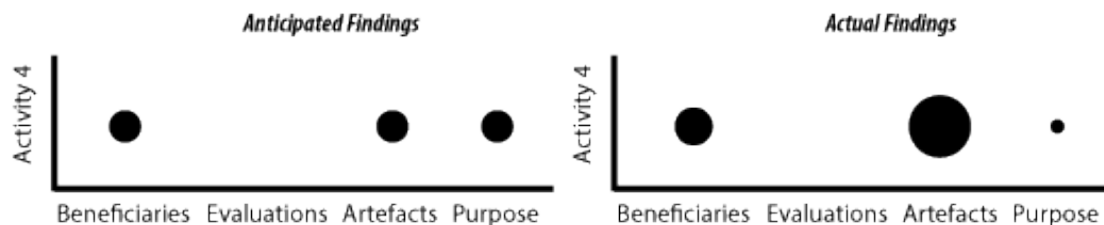


Figure 4.9 - Proportional Abstract Design Situation (PADS) of Activity 4

This showed the ‘uncertainty’ nature of using a design process and the need for a reflective cycle to reevaluate anticipated and actual findings.

4.10.3. Progress in Iteration 1

Activities 1-4 enabled consideration of the credibility and viability of the initial proposed artefact envisaged in Activity 0 via *integration* across *artefact*, *beneficiaries* and *purpose*. Design Arena Progress lists were used to track options for *purpose*, *beneficiaries* and *artefacts*.

Activities started with an assumption that a care circle would consist only of the parents or legal guardians (at this point the research was focused on children with

disabilities rather than disabled individuals generally). With each activity, the potential membership of care circle increased from one or two to over 12, over 14, over 16 and over 20, which also showed this list may not be exhaustive. While identification of additional *beneficiaries* was not the key aim of these activities, this was indeed a key outcome. The identification of additional care circle members resulted in an improved understanding of care circle roles and responsibilities, and their relationship to specific activities and environments.

A decision drawn from Activities 1-4 is that it is not advisable in the design process to consider AT separately from the environment and the tasks that need to be carried out. However, this would greatly complicate the model envisaged in Activity 0 required to support AT choice and use, as it would need to extend to multiple environments and tasks. In addition, it was not possible to generalise the needs of individuals with special needs, which meant the needs of each user of this system would be different.

A care circle's primary responsibility is continuous care for a child across a range of environments such as home, school, and social spaces where the child communicates with a variety of people, rather than simply choosing AT and supporting its usage. Thus, Activities 1-4 not only extended the members of care circle, but they also identified further *purposes*, based on the realisation that the *artefact* would need to provide social support across environments and tasks beyond mere decision making for AT choice and use. Therefore the primary focus of the *artefact* shifted to that of a social and information support system with networking opportunities within and between care circles that goes beyond the capability of a standard DSS. This led to the initial concept of a DSS being replaced by the concept of a social network plus information resource with a potentially wide range of capabilities where options, capabilities and preferences have to be established via dialogue.

From the findings from Activities 1-4, the following broad conclusions were reached.

- Each disabled person is an individual whose needs differ, even if they have a similar medical diagnosis. Their medical diagnosis is not a sufficient indicator of their ability or disability. Therefore what we provide should cater for their individual needs, not the diagnosed biomedical condition.

- Each disabled person has a different care circle that contributes to his or her condition differently.
- Each individual has needs across several environments and several tasks.
- The assessment approach in each centre may also differ according to the assessors and organisations involved. The *artefact* should therefore be sufficiently adaptable to any of these approaches.

The understanding of *design arenas* shifted with the findings in Chapter 4, as presented in Table 4.3.

Table 4.3 – Iteration Shift for Chapter 4

	<i>From</i>	<i>To</i>
<i>Artefact</i>	Choice and use model for decision support tool	An embryonic comprehensive platform for multiple benefits including features for social networking.
<i>Beneficiaries</i>	Immediate family and child	Care circle and additional stakeholders, and child
<i>Evaluation</i>	No evaluation in mind	Feasibility of potential DSS was considered and discarded
<i>Purpose</i>	Support selection and use of AT for a child	Deliver multiple benefits; plus adverse outcomes to avoid, and costs to reduce

4.10.4. Resource Functions Analysis

As early stage research, Activity 0 was *adumbrative* and started outlining and scoping the potential artefact. The activities that followed sought to discover more information and therefore, the most common resource functions were *inquisitive* that resulted in being *informative*, since these activities were aimed at increasing understanding of *purpose*, *beneficiaries* and the potential *artefact*. Some findings went beyond informing the design and were *directive* in finding out further information and *invigorative* in initiating further inquisitive activities.

Both the perceived structure of a care circle and a care circle in relation to frequency of contact was *expressed*. In addition, consideration of a DSS as a solution was also abandoned. The resources had functions similar to those anticipated in Chapter 2. The findings from all activities collectively and cumulatively also realised further functions (Table 4.4).

Table 4.4 – Realities of Resource Functions in Iteration 1

<i>Activity</i>	<i>Resource/Approach</i>	<i>Achieved Functions</i>
<i>Activity 0</i>	DSS knowledge	Adumbrative
<i>Activity 1</i>	Interviews	Inquisitive, Informative, Invigorative
<i>Activity 2</i>	Participant Observation	Inquisitive, Informative, Invigorative, Directive
<i>Activity 3</i>	Interviews	Inquisitive, Directive, Informative, Invigorative
<i>Activity 4</i>	Autobiographical reflection	Directive, Informative
<i>Cumulative Function</i>		Adumbrative, Invigorative, Expressive, Integrative

This chapter described how exploratory research activities were *inquisitive* towards *beneficiaries*, provided *information* and *direction*, and were *invigorative*. The worth integration table was *integrative* of findings from all activities and *expressive*. The activities also assessed the potential of a DSS as an AT support, selection and use tool and arrived at the conclusion that a more flexible Socio-Technical Solution with social networking capabilities is required to meet the needs that were identified, thus shifting the scope of design arenas being *adumbrative*. This was also *invigorative* to the planning of the next iteration.

There was no planned activity for *evaluation*. Nevertheless, the viability of the DSS was *evaluated* and the willingness to *evaluate* by *beneficiaries* was also noted. More importantly, as this approach is RtD, there is no requirement to decide on whether the findings are valuable or insignificant at this stage, as knowledge and direction were the expected output for this iteration.

4.11. Next Iteration

Iteration 1 (presented in this chapter) sought to understand how special needs are assessed and AT selection is made, and thus increased understanding of care circle needs and explored how the current situation for care circles could be improved. All five activities (0-4) were effective in shifting to an improved understanding of the problem. The anticipation and realities of progress in design arenas were also *expressed*. These findings challenged the viability of the envisaged DSS. This exploratory iteration improved the understanding of *beneficiaries*, *artefact* requirements and *purpose*.

Iteration 2 (recorded in the next chapter) also aimed to increase understanding of these factors, to study the feasibility of a potential Socio-Technical solution, and also to start focusing conceptualising the requirements.

A literature review into Socio-Technical Systems (Activity 5) was anticipated to identify technical solutions (*artefact*) for a range of *purposes*. An interview with a carer (Activity 6) was expected to provide information on the *beneficiaries*, suitability of envisaged *artefact* and *purpose*. Activity 7 involved interviews with three members of the care circle and was anticipated to produce more than three times the number of research findings of Activity 6 but in the same *design arenas*. Activity 8 was expected to integrate and evaluate the findings from all the activities so far.

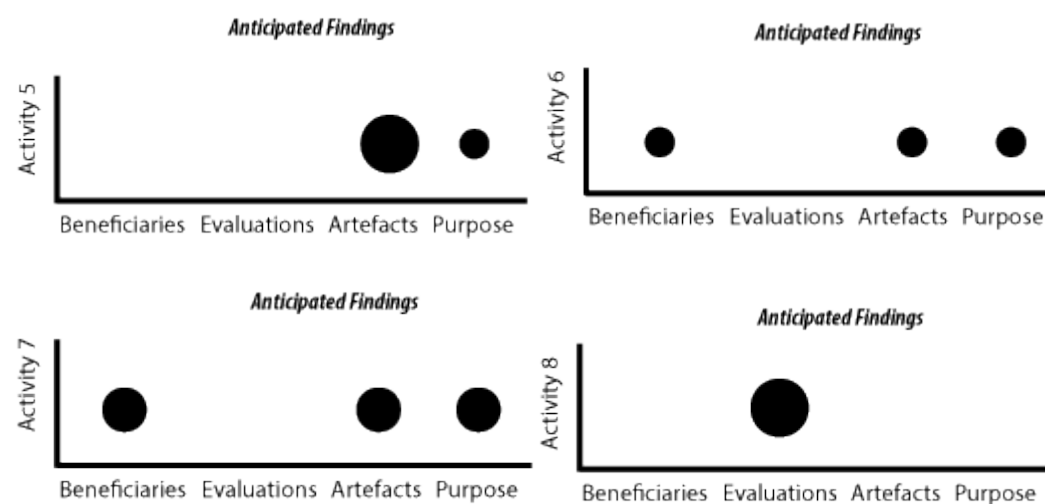


Figure 4.10 - Anticipated Proportional Abstract Design (PADS) Situation for Iteration 2

The anticipated shift of design arenas for the next chapter is shown in Table 4.6.

Table 4.5 - Anticipated Iteration Shift for Chapter 5

	<i>From</i>	<i>To</i>
<i>Beneficiaries</i>	Current understanding of care circles	Improving understanding of professional roles;
<i>Evaluation</i>	Feasibility of potential DSS was considered and discarded	Not known;
<i>Artefacts</i>	Comprehensive multimodal platform with social networking tools	Integrating communication, exploring desirability of socio technical system;
<i>Purpose</i>	Current target benefits and relevant possible reductions to costs and aversions	More holistic understanding of worth for care circles.

Chapter 5 – Iteration 2: Socio-Technical System as a Possible Artefact

Chapter 4 focused on investigating a Decision Support System (DSS) as a possible designed *artefact*. As a result of the findings from Activities 0-4 in Chapter 4, the notion of a DSS was replaced by an idea for a support system via a web platform with social networking capabilities. This meant it was necessary to revisit literature for general insights and information on Socio-Technical Systems (STSs), to see if any existing systems can be utilised.

A Socio-Technical System (STS) is a combination of social context and technology where technology is embedded within a social setting (Coakes, *et al.*, 2000) and could potentially meet the *beneficiaries*, *artefact* and *purpose* needs, identified in Iteration 1 recorded in Chapter 4.

5.1. Research Aims

The ways in which the current situation of disabled individuals regarding choice and use of AT could be improved were explored in Chapter 3 and reflected in identified purposes. A suitable system can be achieved with capabilities identified for a potential *artefact* in Chapter 4, if suitable for the social settings and *purpose* identified in Chapter 4 in relation to *beneficiaries*. Based on Activities 1-4 of Chapter 4, a DSS was deemed insufficient and a system with more complex networking capabilities was required. Therefore a social support and information provision system needed to be investigated.

In the context of this research, the potential artefact should have capabilities usually associated with Social Networks. Online Social networks are social structures that are connected by interdependencies and communicate over the Internet. Social networks can provide opportunities for more frequent information updates and enable most members of the care circle to be present virtually if not physically. This reduces the costs incurred in travelling and time.

The purpose of this second iteration is to identify if the current situation can indeed be improved by designing for a STS and if so, how. The first step in the process is to conduct a feasibility study to determine whether or not the current situation can be improved by designing for a STS, and also whether the STS is sustainable.

Finally, it needs to be established if such a system is desirable to the potential users.

5.2. Activity 5 – Socio-Technical Systems

Having made the decision to explore STS, the first activity of this iteration was to conduct secondary research on this subject. ‘New Socio-Tech’ is applying human, organisational and technological facets of socio-technology to current IT realities brought about by digital communication in the new millenium.

5.2.1. Method

Following the conception of the idea for a social support and information provision system, a variety of approaches to STS from the book, *The New SocioTech: Graffiti on the Long Wall* (Coakes *et al*, 2000) were explored. This book provides a global perspective from a variety of projects based on existing principles and features that are discussed in this section. This source was used as an entire activity as it is the most up to date literature on STSs and is a collation of chapters by several authors. It is also edited by Coakes and her team who have been well-established sources in this subject for several years.

5.2.2. Findings

Firstly, the findings explain what virtual organisations as instances of STSs are, with a view to supporting the requirements of the care circle as identified in Iteration 1.

STSs result from interaction between humans, human activities, spaces, artefacts, tools and communication media (Cherns, 1976). STS theory states that software technologies should never be designed or introduced without considering the softer issues such as the organisation or context of usage of the technical system (Cherns, 1976).

A STS can provide a means to the various ends of all group members and is pervasive (Coakes *et al*, 2000, p.9). In approach, designing for an STS involves both social science and technology. A STS has the potential to be more integrated and holistic rather than simply being a combination of social and technical as the name may simply suggest (p.6). The motive of the *new* STS is to integrate information technology with dynamic communication (p.9), both synchronous and asynchronous (p.10).

As the system will support vulnerable individuals and deal with a social issue, ethical issues need to be considered. These can be fully supported by STSs, as they should be grounded in ethical and moral principals (p.11) by virtue of their social elements. According to Lin and Cornford (2000, p.52), Mumford (1996) describes how STSs could be approached in macro environments in the context of change. The key ideas defined are:

- “Incorporation of *ethical* choices and principles that affect social outcomes;
- Commitment to *participation* in developing work structures;
- Focus on *design* to accommodate new technologies; and
- The *autonomous workgroup* as a self-organising entity, which is able to take responsibility for its own design activities”.

While an approach to STS recognises the interaction between systems and its users, the social characteristics that lead to a successful implementation and usage of these systems are due to the ethical aspects where people are continuously involved in the change process. This is a useful insight to consider during the design and development process of the envisaged artefact.

Improvements in digital communication have enabled virtual organisations as a new form of STS. Ahuja (2000) defines a virtual organisation as a, “geographically distributed organisation whose members are bound by a long-term common interest or goal, and who communicate and co-ordinate their work through information technology” (Ahuja, 2000, p.171). A virtual social media based platform that is both synchronous and asynchronous, could also include a knowledge base. If the STS is to include a Knowledge Management System (KMS), it cannot be autonomous as it should not predict decisions. Decisions need to be made jointly by members of the

care circle. The characteristics of a KMS virtual environment might include: the tasks to be carried out; the role of the user; the status of a task; the structure of the system; interaction patterns; and information exchange (Ahuja, 2000, p.171). Following implementation, the characteristics of the KMS could be monitored to study the effectiveness of the virtual care circles (p.182) and how the requirements of the system are met.

According to Lin and Cornford (2000, p.52), Cherns (1976, pp. 783-792) describes socio-technical design as having nine key principles in the following three categories:

1. Express ideas about the nature of design tasks: *compatibility* with objectives, design that expresses *essential requirements*, and *incompletion*;
2. Expressing ethical and ideological assumptions of STS: *multifunction*, *information flow*, and *design and human values*;
3. How well-formed STSs fit within organisations: control awarded to work team, political boundaries are well managed and established within a social support of desired behaviour: *sociotechnical criterion*, *boundary location support*, and *congruence*.

An observation is that the first three principles align with *artefact* and *evaluation* the last three align with *beneficiaries* and *evaluations* and also the care circle. The principles in the second point align with *worth*. Keeping these nine principles in mind helps to continuously evaluate the achievement of purpose of the system during the design process.

The next section explores some features that could be part of a STS for care circle support, based on literature.

5.2.2.1. Features and Capabilities

According to Mumford (2000, p.34), technology is acquired, implemented and used to meet a need or problem (p.33) and to give users freedom in opportunities for choice. This choice assists attainment of a desired beneficial future, i.e. worthwhile.

Within the work environment, this aids senior team members or managers in breaking out of a narrow outlook, illegitimate use of power and authority, counterproductive

organisational cultures and enhances knowledge sharing and an increase in productivity. Although Mumford (2000) does not address social networks, a similar principle can be used to nurture a collectively sustainable online culture. If this is done considerately, freedom for the communication of the disabled can be enhanced with effective involvement of the care circle.

For such choices and decisions to reflect the wishes of a group, two conditions are required: (1) participation (2), effective communication (p.34). Mumford (2000, p.35) states “The principle objective of a STS is to make work more satisfying for the *individual and group* doing it, while at the same time enabling them to contribute to a high level of technical efficiency”. The role of a STS is to support or enable human agency and work more satisfying. However, Mumford (2000) has referred to STS having an objective rather than the individuals or groups using it. Based on Mumford’s insight, the following features and considerations can be adopted in this research for care circles in a potential STS.

1. The membership should only be upon invitation and approval of the legal guardians of individuals with disabilities.
2. These circles should be non-hierarchical and feedback should be confirmed and re-confirmed. For example, if a parent posts a question, a peer or professional can respond. In addition, if questions can be posted publicly, this would open an opportunity for non-care circle members to respond.
3. Aram (2000) discussed chat groups and TeamRooms (p.167). Chat groups were identified to be giving fuller choice to engage in the ‘unfolding life of the group’ where anyone with access to the chat can join, compared to TeamRooms, which are predefined and members know each other well and already work together face to face. Care circle memberships are in a way predefined but similar to the characteristics of chat groups, chats are started for variety of purposes which may influence the membership.
4. The behaviour of these groups may range from destructive where groups end up breaking, dysfunctional where relationships are incompatible up to productive engagement.
5. Members should also be allowed to communicate privately.

6. What people say are interpreted by their words, intonation, facial expression, gestures (Carroll, 1974), making a social space with options for text, audio and video based chats an ideal communication (p.37). An opportunity for a multimedia social space should be available in the proposed design solution.
7. Communication that is not reliant on participants being at the same location can increase the possibility of participation by eliminating physical limitations and improve the quality of participation. This also creates a space for silence without offence or non-confrontational rejections to take place. However, this may also result in loss of individuality as it is possible to communicate without any personality (p.38).

While creating care circles by way of a virtual social network would increase speed and efficiency in communication, it will also make the care circle (world) smaller (Aram, 2000, p.161) by bringing together care circle members separated by distance. According to Aram (2000, p.161), as a means of communication with minimum personality, the web also has: potential risk for participants of identity, risk of unwelcome and unwilling intrusion, fragility of sense of self, taking offence, unpredictable, and potentially destructive relationships. This can be evaluated during design, identifying whether risk outweighs benefits.

5.2.2.2. Principles

The primary principle to consider in a potential STS is the needs of the organisation and individuals (Coakes *et al.*, 2000, p.11). Once what you want to do (the purpose) and the process have been decided, the decision of whether any technology (the artefact) can help and if so, how the potential technology could be explored (p.12) makes the actual choice of artefact secondary. This is similar to the classic waterfall engineering model but is too restrictive and a more flexible approach that is iterative and parallel was chosen for this research. In the chosen approach neither the process nor the purpose needs to be decided nor fully understood first.

Munkvold (2000, p.14) presents key principles in STSs as: joint optimisation of technology and systems; quality of work life; participation and semi-autonomous work groups. The quality of work life is analogous with the quality or the capability

of disabled individuals, while the semi-autonomous work groups correspond on to the care circle of the child.

Designing for a STS is compatible with ICF's holistic approach to disability. An STS:

- involves the potential users of the system as part of the development;
- takes into consideration business processes; and
- fits in within the broader environment and
- fits into the chosen paradigm (i.e. RtD).

5.2.2.3. Organisational Design

Structuring a virtual care circle can be compared to an organisational structure. Organisational design looks at business processes and stakeholder procedures, the way teams are organised, and decentralises the decision making about use of IT (Munkvold, 2000, p.17).

In a care circle, it is not possible to have a team leader or parent make decisions, as while the legal guardian makes the final decision, the discussions need to be decentralised. This also means that individual members cannot be empowered to make independent decisions and act upon them. The organisation of the care circle and the communication structures must be clarified in order to make decisions about disabled individuals whom they care for. Chapter 4 made a start in understanding communication structures, but this requires require further investigation to establish how this should be reflected in the artefact.

A STS should be based on clearly defined technical and social boundaries. The relevant information should go directly to care circle members, which effectively means the care circle members may need to work across cultural and personal boundaries in all settings of communication (Aram, 2000, p.161).

The tasks created in the social network for care circle members should be easily contained within the boundaries of the system and be intuitive. Once the constraints have been identified, Stacey (1996, p.176) lists five control parameters to establish if the system could work within the boundaries: rate of information flow, degree of diversity, richness of connectivity, level of contained anxiety and the degree of power

differentials. Once a suitable system has been built and is live, these parameters can be used to establish boundaries.

5.2.3. Summary

All findings were *informative*. Similar to the activities in Chapter 4, this summary lists its findings according to design choices.

- *Beneficiaries:*
 - B16: All members of the care circle are considered beneficiaries. This is a broader view from Iteration one where care circle members identified in Activities 1-4 were considered beneficiaries;
- *Artefacts:*
 - A25: Should consider ethical issues (eg. data protection) when designing (*ameliorative*);
 - A26: The *artefact* should include both synchronous and asynchronous communication to bring together geographically distributed users;
 - A27: Facilitate decentralised decision making that is focused on disabled individual;
 - A28: Membership should only be upon invitation and authorisation by the legal guardian;
 - A29: It should support members of care circle during assessment, diagnosis and provide continuous support;
 - A30: It should enable chats and forums;
 - A31: Should enable private 1-2-1 chats.
- *Purpose:*
 - P7: The *artefact* should improve quality of life of the disabled individual by supporting the care circle members (*ameliorative*);
 - P8: Provide a comfortable environment where rejection or silence can be communicated without offence (*ameliorative*).

The review of STS recorded in Activity 5 was expected to be primarily *informative* but it was also *ameliorative* as it provided guiding principles for STS in this research.

5.3. Activity 6 – Discussion

A carer of a disabled individual was identified to have a discussion about the potential design solution. This activity was expected to be *protective* by obtaining feedback from potential users prior to making concrete plans or development; *inquisitive* as a discussion and the findings obtained would be *informative*. It was hoped that the response from the participant would confirm the existing scope, which would be *adumbrative* in function.

5.3.1. Participant

The participant was a personal contact and carer of her 41- year-old sister who has Down's Syndrome. She discussed her experience as a carer and needs to support her sister with the researcher, which is discussed in this activity.

5.3.2. Method

The participant was provided with a brief background of the research. Thereafter the idea of a potential social network with information resources was presented and opened for discussion. A rough sketch of the care circle (Figure 5.1) was used for the discussion. This discussion lasted for approximately an hour.

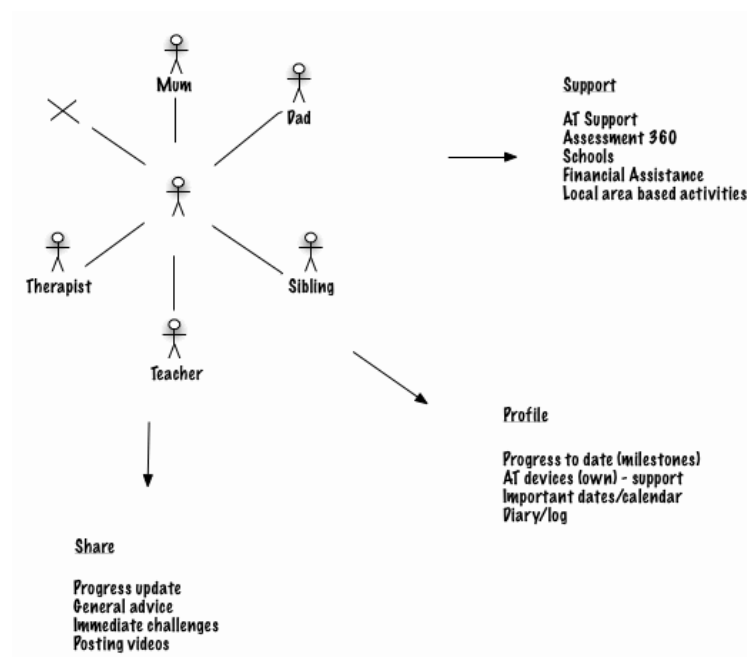


Figure 5.1 - Sketch of Potential Virtual Care Circle and its Capabilities

5.3.3. Findings

The participant is a few years younger than the older sister whom she cares for. She mentioned that having a communication method that could be used between all members of the care circle was essential. She mentioned numerous mistakes that had happened, both in school when they were younger and in medical care, due to the lack of such a tool. For example in one incident, her sister explained to the school that her sisters were unwell and had been in bed by drawing an image of them resting in bed. The school mistook this for one of her sisters being dead based on her drawing and got her classmates to create a condolence card for her family. If a better communication system was available, such misunderstandings could have been avoided. The participant also stated that although it would be ideal to have the doctor or general practitioners involved in communication device related decision making, currently this may be possible only in the case of a residential doctor and a care home.

The schools she had attended through to College, had also continuously helped the participant's sister with life and independent skills. This included routines such as going shopping; paying for things and collecting change or taking washing out of the machine, drying them and folding them. The training had potential to be more affective when it is continued at home and a shared platform where these skills are shared will be very useful.

5.3.4. Summary

This activity was expected to be predominantly *inquisitive* in exploring a family member's receptiveness the potential *artefact*. However, this was also a largely *protective* activity, as prior to developing an *artefact*, identifying its potential would increase the success of a design solution. In addition, this activity was also *informative directive* to carry out a similar activity with professional members of the care circle (recorded as Activity 7) and *invigorative* in wanting to reduce miscommunications. As the preliminary idea for a virtual care circle with social networking capabilities was explained using sketches, it was also *performative*.

The findings from Activity 6 specific to a care circle concerning *beneficiaries*, *purpose* and *artefacts* are listed below. Personal responses from the activity findings are also included.

- *Beneficiaries*:
 - B17: Care homes are a potential beneficiary;
- *Artefacts*:
 - A32: The *artefact* should be a shared, transparent communication platform for all care circle members (personal response).
- *Purpose*:
 - P9: To reduce misunderstanding between families and schools by improving communication by having a shared information and communication system (*invigorative*);
 - P10: To enable continuous training and support of school activities at home (personal response).

Overall, the concept of a social network remained suitable and gained further support. As a family member had confirmed the suitability of the concept, the next step was to verify if it was the same for professional participants.

5.4. Activity 7 - Interview

New *artefacts* have to be demonstrably more effective than existing solutions to be successful. Therefore following discussion of a potential system with a carer (in Activity 6), combined with the findings from Activity 5, the idea was raised with professionals for verification with paper sketches and a list of questions for the potential system. Further interviews were conducted to improve understanding of present communication patterns, ideal communication methods, and care circle attitudes towards Social Networks.

5.4.1. Participant

The interview was with the Occupational Therapist (OT), who is also the Head of Assessment, whom I met during my previous visit to the Centre (recorded in Activity

1). The OT had also arranged for another Occupational Therapist (OT2) to join us for a specific discussion on social networking.

5.4.2. Method

An appointment was made with the Centre where Activity 1 was conducted. This was for a structured interview during which the interviewees were shown the paper sketch used in Activity 6 of a proposed social network system (Figure 5.1).

The questions, their aims and types are listed below (Table 5.1):

Table 5.1 - Questions for Interview

What form of regular support do you provide for families with special needs children?	
Aim: Explore purpose/responsibilities of beneficiaries	Question type: Open
(a) Do you currently have a forum, physical or virtual social network or support groups?	
Aim: Explore artefacts (competitive products)	Question type: Closed
(b) What key Activities do the support groups provide?	
Aim: Explore artefacts/ competitive products details	Question type: Open
What are the current challenges with these support groups?	
Aim: Explore purpose/reduced costs/aversions	Question type: Open
Do you think a social network could solve or help solve challenges in: communication, updates, travel and expenses?	
Aim: Desirability	Question type: Closed
Do you see social networks addressing any other challenges?	
Aim: Desirability/Purpose	Question type: Open
Are there any restrictions on being part of a secure social network?	
Aim: Desirability/Purpose	Question type: Open
In your opinion, how capable are the members of care circle in using social networks?	
Aim: Explore purpose/desirable costs	Question type: Closed
How often do you think people will be able to use social networks?	
Aim: Explore purpose/desirable costs	Question type: Closed

Similar to Activity 1, an overview of the aims of this research along with the questions and the Social Networking idea that had evolved were forwarded to the OTs (see Appendix C5 –Proposal) in advance. In total, the interview lasted for approximately ninety minutes.

5.4.3. Findings

The session commenced with a reminder to both OTs of the research and the purpose of interview. Prior to proceeding to the interview questions, the OT provided an update on a change to government funding provision since Activity 1 was carried out, that confirmed the continuing relevance of this research. The following two methods were available at that time:

1. Service Level Agreement (SLA) with the Local Authority and NHS that comes with funding and package of care.
2. Referred to the Centre by the Local Authority but self-funded. Carers would normally require a quotation prior to assessment (which they are unhappy with as it is case specific). The Centre offers the carers with four options (£700 – £4,800) and asks them to choose or tailor the package according to their need and funds at their disposal.

Responses to the questions are as follows:

1. The forms of regular support provided for families with special needs children are:
 - Phone
 - Email
 - Chatterbox Club (groups where families met informally)
 - Onsite training to use AT devices
 - Annual reviews of choice and use of AT and support plan
2. On physical and virtual interaction opportunities, both individually and in groups and what activities are supported:

The Centre offers follow-ups but these are quite expensive for most clients.

Included in the fee are:

- a) Initial support for the care circle on the day of assessment;
- b) Thereafter, carers being able to phone in or email an assigned professional anytime;

- c) Carers are invited to attend the Chatterbox Club meeting twice a year. This is a peer networking opportunity for parents, siblings and children, as they do not meet similar children once they start mainstream schools;
- d) Carers can use Google Groups, that provides a virtual space for information discussions and
- e) Virtual support from AT/AAC service providers is available but onsite training for customising AT/AAC is also provided by the Centre.

The Centre attempted teleconferencing approximately five years ago, but this was not successful.

3. The challenges with these support groups are as follows:

- All care circle members are required to get to the Centre, which is inconvenient;
- Personal preferences; some carers may, for example, prefer the Chatterbox Club over other activities;
- Significance of need can decrease, as a need may cease to be urgent or the care circle learns to adapt to a new need that might leave participants no longer interested;
- Carers attend the groups only when they have an immediate need and they may have to wait for up to six months for the next one.

4. At this point OT2 joined us. She agreed that a social network could solve or help solve challenges in communication, information updates, travel and expenses as support and follow up were immediate needs for their patients.

5. She added that social networks will not be a replacement for main assessments but could be beneficial for post assessment, which is quite expensive. It would also provide a broader view in assessment and also support post assessment strategies.

However, there may be practical challenges, for example the lifestyle of the OT where he or she may not wish to use social networks and professional inhibitions such as NHS staff only being able to access non-authorized systems or work information remotely.

The care circles could be provided with: more accurate and up-to-date support; information on funding; support during transitions between schools; and educational tribunal support, where carers may not be aware of their rights or where to access necessary information on their legal entitlements regarding obtaining support. Shared technical support as part of a system may reduce dedicated AT support costs and training costs.

6. OT2 stated that NHS professionals (eg. GPs) involvement will be the biggest challenge due to their own regulations that might prohibit them from using external systems or participating in external care related initiative. In addition, the care circle is normally fairly open but requires a need for ‘off the record’ conversations.
7. OT2 confirmed that the capability of care circle members will not be an issue if the Social Network is usable. However, willingness to commit to using the system would be a challenge for some parents, especially those with more than one child and struggle with time commitments.
8. Care circle members should be able to use the Social Network on the basis of need and without obligation. The Centre is currently discussing the need for a virtual environment.

5.4.4. Summary

Activity 7 was primarily expected to be *inquisitive* in function but was *directive* in its preparation, *expressive* in the sketch; *performative* in the demonstration of the sketch. Findings were *informative* and *invigorative* from the additional clarifications that had to be obtained. However, this activity was also *protective* in identifying and confirming needs, benefits and preferences on the proposed design solution prior to developing it.

The findings identified in Activity 7 specific to a care circle and relating to *beneficiaries*, *purpose* and *artefacts* are listed below.

- *Beneficiaries*:
 - B18: Social workers can avoid wasted visits as first identified in Activity 4 of Chapter 4 (*protective*);

- *Artefacts:*
 - A33: The artefact should support the continuous care circle membership (personal response);
 - A34: The artefact should facilitate/enable alternative and continuous self-assessment by a legal guardian of the child with disability to supplement the annual or bi-annual appointment (*invigorative*, personal response).
- *Purpose:*
 - P11: Lack of initial advice and support was identified in Activity 4 of Chapter 4. This current activity supported that finding (*protective*). It also suggested an aim for the design solution as providing initial support together with advice for first assessment for inexperienced parents.

5.5. Activity 8 - Application of CAT Model

Now that an STS supported by social networking technologies has been confirmed as a possible solution, an evaluation was carried out to decide whether to use an existing social network or to develop a new one. As a structure built on the ICF model of disability, the Comprehensive Assistive Technology (CAT) model was chosen to evaluate the suitability of a range of existing networks. Section 3.2.5 explains the CAT model developed by Hersh and Johnson (2008). This section records the application of the model as it was intended by Hersh and Johnson (2008) to:

1. identify gaps in AT provision;
2. evaluate existing AT systems;
3. support the design and development of new AT devices; and
4. support design for all.

The findings from this activity assisted with the assessment of the current situation with AT (with no/limited internet support) and the exploration of the potential of existing social networking solutions.

Potential solutions and their feasibility need to be studied to meet the identified *purpose* of *beneficiaries*. The CAT model addresses four different domains: *person*, *context*, *activities* and *AT*. The findings from using this model are presented with

labels and tables that break down these four domains into further categories, requiring comments. The expected application of the model for an individual. However the model is extended in its use in the context of this research to comment on the potential care circle, which is a minor original contribution to knowledge.

5.5.1. Participant

The researcher conducted the major part of this study and where necessary, web developers were consulted with regard to technical details.

5.5.2. Method

The information obtained from Activities 0-7 in Chapters 4 and 5 (not limited to DAP list) and personal knowledge provided, the information required in this model was completed. Hersch and Johnson (2008) built two types of application models, *table* and *label attributes*. The first part of the CAT model application in this activity pulls together potential barriers to communication between care circle members both with and without the use of the computers and Internet, indicating potential reductions in accessibility barriers. The *table attributes* of CAT is used for this purpose. This is followed by the application of both *label* and *table attributes* of CAT in order to assess how a potential design solution could meet the needs of the care circle by improving accessibility through social networks. This was done by evaluating six existing mainstream social networks: Facebook, LinkedIn, Flickr, Bebo, Foursquare and Hi5. The items on the tables and lists were taken from the case studies of Hersch and Johnson (2009b) and adapted for the chosen case study of this research.

5.5.3. Findings

5.5.3.1. Identifying accessibility barriers of care circles

The first barrier is that not all care circle members will have access to the Internet even though 70% of UK's adult population have Internet access and 60% have broadband access (Office for National Statistics, 2010). There is a possibility of those who do not have access to the internet or those who are barred from accessing social networks due to work-related policies.

The Person and Context sections of the CAT model were used to understand other possible barriers by looking at the requirements and the needs of the motor impaired individuals and members of the care circle using the checklist approach.

The *labelled* template was used to record the context. *Table* templates were used to compare situations with and without Internet access.

The first section presented here is a labelled attribute presentation of the CAT model.

Person (P):

P.1 Characteristics:

P.1.1 Personal information: Disabled individuals of all ages, both genders, diverse fitness, lifestyle and educational needs;

P.1.2 Impairment: Could have sensory, learning or motor impairment. Motor impairment here means that, with support, the person is able communicate;

P.1.3 Skills: Basic motor skills, though coordination is reduced, able to follow instructions given verbally, or using audio-visuals;

P.1.4 Preferences: communicate with all involved in their regular decision-making, active life, doing things themselves with technology if necessary, but without personal assistance.

P.2 Social aspects:

P.2.1 Community support: Most individuals have support from family members, medical and educational practitioners. Some also have support from friends and/or local community/organisations;

P.2.2 Education and employment: Actively involved in either vocational or academic education.

P.3 Attitudes:

P.3.1 Attitudes to assistive technology: Willing to use assistive technology as long as it is fun, entertaining and helps them communicate with care circle

members and provides them with more independence. Slightly older children are also concerned with its appearance;

P.3.2 General attitudes: independence is important, but compared to older individuals children seek gradual independence.

Context (C):

C.1 Cultural and social context:

C.1.1 Wider social and cultural issues: All children in British schools speak English with some children who understand or speak a second language but there are members of the care circle for example, grandparents who do not speak English;

C.1.2 User's social and cultural context: Diverse multicultural society but adapt to local cultures.

C.2 National context:

C.2.1 Infrastructure: Modern infrastructure, newer technologies, Assistive Technology is used and computer and Internet access is available to most;

C.2.2 Legislation: Disability discrimination legislation and accessible web content guidance in place with increasing enforcement;

C.2.3 Assistive technology context: A wide range of assistive technology is available and there is some financial and other support to obtain them. Facilities for repair and maintenance are also available. There are challenges in identifying and using the most appropriate device with some of them ending up in the cupboard unused.

C.3 Local settings:

C.3.1 Location and environment: Classroom, school environment, home, work and other regular social settings;

C.3.2 Physical variables: Moderate temperatures, sometimes noisy and/or crowded environments.

Table 5.2 shows the outcome of CAT's checklist approach to identify potential barriers to communication between care circle members in social networks both with and without the use of the computers and Internet, indicating potential reductions in accessibility barriers.

It shows the accessibility challenges of children with sensory, learning or motor impairment and their care circle members. Taking into consideration that a virtual or online solution is being considered, the potential impact is shown in the right column, with some details of potential web-based solutions and the design arena that it corresponds to, *Beneficiaries (B)*, *Evaluation (E)*, *Artefact (A)*, *Purpose (P)*. This is similar to the DAP lists recorded in other activities and will be carried over as the findings from this activity.

The next section presented here is the tabled attribute presentation of the CAT model.

The labelled attribute representation is followed next by the table form. Within Table 5.2, plain text indicates no accessibility barrier, *italic* indicates *mild* barriers; ***bold italic*** indicates *moderate* barriers, and **bold** indicates *severe* barriers.

Table 5.2 - Application of CAT Model

Accessibility barriers for care circle members for communication			
Category of Activity	Accessibility status for communication of care circle		
	Without internet	With internet	Explanation
Communication and Access to information	All information only locally available	Information locally and remotely available (A)	Information is available to care circle both online and in hard copy.
	Access to information locally available or personal copies	Access to digital copies available on demand (A)	Personal knowledge and Activity 1 (A5, 7-8)
	<i>Telecommunications</i>	Email, chats, forum, groups (A)	Online has more options that offline for communication.
	<i>Low tech devices</i>	<i>High tech devices</i> (A)	Each form of technology excludes different users.
	Observations, visual, audio, text	Observations, visual, audio, text (A)	Internet provides access to wider information.
	Travel time and cost	Minimum travel time and cost (A)	Not everyone is available to attend meeting at the same time and location (Activity 1).
Mobility	Travel to meetings	Access needed to internet (B)	Not everyone is available to attend meeting at the same time and location (Activity 1).
	<i>Fine motor skills i.e. writing</i>	Accessible input/output (A)	Care circle members may also have disabilities.
	Synchronous discussion	Synchronous and asynchronous discussion (A)	Not everyone is available to attend meeting at the same time and location (Activity 1).

Accessibility barriers for care circle members for communication			
Category of Activity	Accessibility status for communication of care circle		
	Without internet	With internet	Explanation
Cognitive Activities	Analysing, assessing and evaluating information	Analysing, assessing and evaluating information (B)	Internet significantly improves access to information. Additional cognitive activities can also be carried out synchronously and asynchronously without any limits on time.
	<i>Logical, creative and imaginative thinking</i>	Logical, creative and imaginative thinking (B)	
	<i>Planning and organising</i>	Planning and organising (B)	
	<i>Decision making</i>	Decision making (B)	
	<i>Categorising</i>	Categorising (B)	
	<i>Calculating</i>	Calculating (B)	
	<i>Experiencing and expressing emotions</i>	Experiencing and expressing emotions (B)	
Daily living	Personal care and hygiene	<i>Personal care and hygiene</i> (P)	Can be better monitored in person.
	One to one support	Peer and expert support (P)	Different opportunities but without barriers.
	<i>Environmental control</i>	Virtual environmental control (A)	More control within VLE than in a real environment.
Education and employment	Learning and teaching	E-learning and teaching (A)	Both environments provide similar opportunities.
	Individual and group based Activities	Emails, chats, forums and conferences (A)	
	Curriculum and therapy	Curriculum and <i>therapy</i> (A)	Online therapy is limited compared to face to face.

Accessibility barriers for care circle members for communication			
Category of Activity	Accessibility status for communication of care circle		
	Without internet	With internet	Explanation
Education and employment	Indoor and outdoor Activities	Social gaming activities (A)	The nature of online and physical games are different.
	<i>Extra curricular Activities</i>	Extra curricular activities (A)	Motor impaired individuals will have more challenges doing physical extra curricular activities than online ones.
	Occupational therapy	<i>Occupational therapy</i> (A)	Online therapy is limited compared to face to face.
Recreational Activities	Home, school and other clubs	Different online groups (A)	The nature of online and physical groups are different.
	Individual and team based	Online gaming (A)	Types of gaming opportunities are different.
	Holidays and visits: museums, galleries, heritage sites	Web browsing (A)	Types of activities available are different.
	Indoor and outdoor sports	<i>Indoor and outdoor sports</i> (P)	Online sport activities are limited.
	Art and handcrafts	<i>Art and handcrafts</i> (P)	Not possible to instruct and check art and handwork as easily online.
	Social events	Online social events (A)	The types of events are different.

Based on the findings from Table 5.2 that identified accessibility barriers, the third type of application reverts to using numbered labelled form of the CAT model. It is used to assess existing social networks to identify how a potential design solution could meet the needs of the care circle by improving accessibility.

The next section presented here is once again the *labelled* attribute presentation of the CAT model but is used for the choice of appropriate AT based on the identified context.

Activity (A) - Assessment for choice of appropriate assistive devices

Assistive Technology - AT

AT.1 Activity specification

AT.1.1 Task specification:

Involvement of all possible members of care circle, who would potentially be communicating with the individual using the assistive device (B);

AT.1.2 User requirements Convenient and user friendly interface with access to a single platform; entire care circle should be able to participate at the discretion of the parent or legal guardian of the individual with disabilities; should not demand additional time or cost in travel; should be able to obtain continuous support from the distributor and decision maker (A).

AT.2 Design issues

AT.2.1 Design approach: Design for the disabled individual and members of the care circle an accessible interface where they could log in, discuss and make decisions about care securely (A). The interface should be inclusive of many types of disability and web-based (B).

Architecture: Web-based social network where a few people have the rights to approve members of the care circle to be involved with the disabled individual. This network could be accessed remotely either by a personal computer or a mobile phone-based device.

Device realisation: the disabled individual's profile, calendar with events, chats, videos, technical support for the assistive devices, and any other up-to-date discussions could be shared according to the privileges assigned by the parent or guardian.

Options: The interface should be compatible with still images, audio, video and text information (A).

AT.2.2 Technology selection

Input: The user should be able to access and interact with the information by keyboard, mouse, touch, stylus or any other assistive device that they would otherwise use to interact with the personal computer or smart phone (A).

Output: The display should be compatible with most computer resolutions and mobile phones; if necessary, individual applications should be made for mobile phones (A).

Programming: Could use any language that does not work against web accessibility guidelines (A).

AT.3 System technology issues

AT.3.1 System interfaces

Standard accessible web components should be used to reduce the need for specialised plug-ins (A).

AT.3.2 Technical performance

The system needs to be secure as sensitive information relating to a vulnerable individual would be included; Data Protection and Privacy related legislation might also apply due the nature of information concerned (A).

AT.4 End-user issues

AT.4.1 Ease and attractiveness of use

The system needs to be informative, robust, usable and provide options to include users with visual impairments; design themes for personal preference could also be provided (A);

AT.4.2 Mode of use

Whenever possible there should be an option of online and off-line modes (A).

AT.4.3 Training requirements

Information should be arranged with the best possible architecture within the platform to reduce the necessity for training; suitable help should be provided (A).

AT.4.4 Documentation

There should be an archive feature for all information and an option to print any information for those who may require a hard copy; this option should be bound by a data protection agreement.

Throughout the applications of the CAT model, six existing mainstream social networks: Facebook, LinkedIn, Flickr, Bebo, Foursquare and Hi5 were considered and ruled out as none of them meets the requirements. This application of CAT Model was also published as a conference paper (George *et al.*, 2010).

5.5.3.2. Investigation of Possible Artefact Using Existing Solutions

Based on the findings, an attempt was made to develop a social network using *Ning* (2009), which is an online system that provided pre-fabricated solutions to create and manage a social network. The site was accessible at <http://capability.ning.com>. An attempt was made to apply findings from the study of STSs. Some of the challenges were, the restrictive nature of the *Ning* structure, being limited to features that *Ning* offered. This business was a free web-hosting platform, which was then converted into a subscription only model in 2011 and is no longer accessible. While this system

had a potential to include several features, it did not provide the required levels of access, authorisation mechanisms for membership nor provide information repository and did not meet accessibility requirements. Therefore, the idea to use Ning was abandoned. Despite numerous accessibility and conceptual challenges, a social network appears to be the most promising design solution. Hence the decision was made to confirm requirements and build a website with the specified requirements.

5.5.4. Summary

Hersh and Johnson's (2009b) CAT model was used to identify the current barriers for members of care circle and motor impaired persons. This application also extended the model by integrating the existing findings and adding a rationale to the *table* framework. The initial application of the CAT model highlighted limitations of the current situation and identified potential design solution options by exposing the information already identified within a structure. The *label* and the *table* attributes of the CAT model were applied to characterise the social setting of the individual with the disability together with the care circle, and also to evaluate their social needs and identifies accessibility challenges in communication within the care circles and the choice and use of AT. Both Internet-based and physical environments were analysed. The accessibility requirements also emerged to inform the creation of an accessible social network based design solution that could be built for the enhancement of capability of children with motor impairment.

The CAT model in Activity 8 provided a systematic way to evaluate the accessibility of existing social networks and a potential online social networking solution for members of the care circle by providing a framework to understand the design context both with and without internet and also the choice and use of AT. This process also highlighted the *artefact* features, *beneficiaries* and *purposes*. This made the CAT model *integrative* of design choice types from previous activities and provides a framework that is *expressive*. The framework was *inquisitive* and the activity was *protective* as it is based on existing data. It was also *inquisitive* by relying in personal knowledge.

A social network was built using an existing resource *Ning* but it did not fully meet the accessibility requirements and was abandoned.

While the CAT model applications helped organise the existing findings clearly, new findings were limited as it was an integrative activity and it acknowledged aspects of the *artefact*. They are as follows:

- A35: The potential solution should be accessible (e.g. compatible with AT devices). Existing social networks are not accessible.
- A36: The artefact should have a clear visual and content structure (personal response);
- A37: Technical support for artefact usage should be available (personal response).

Evaluation

- E4: 6 existing social networks and Ning were evaluated and discarded.

5.6. Worth Integration Table 2

The findings from Activities 5-8 confirmed some findings from the first iteration recorded in Chapter 4 and produced further findings. As in Chapter 4, a Worth Integration Table (Table 5.3), developed by the researcher, was used to make connections between *artefact*, *purpose* and potential *beneficiaries* (recognising any aversions and risks).

Table 5.3 - Worth Integration Table

<i>Artefact features and capabilities under consideration</i>	<i>Related Purpose</i>	<i>Potential Beneficiaries</i>	<i>Risks of increased costs or adverse consequences</i>	<i>Activity No.</i>
Membership and participation of teachers and teaching assistants and adding members at anytime (A28, A33)	Better integration with educational needs (P10, P11); Improve quality of life of child (P7, P10, P11)	Child and care circle (B17)	None	7
Discussion/forum (A30)	Customise AT device or environment and use; support during assessments, diagnosis and continuously. (P7)	Child and care circle (B17-B19)	Incorrect information	5
Asynchronous and Synchronous modes of communication (A26)	To be finalised (reviews can be informal, frequent and up to date)	Care circle (B17-B19)	None	5
Chats (A30, A31)	To be finalised (to enable informal, off the record conversations, respect to privacy).	Child and new care circle member (B17-B19)	May share incorrect advice	5
Ethical system (A25)	To be finalised (inclusive of users who may have special needs)	Child and new care circle member (B17-B19)	None	5
Transparent communication (A27, A32)	To reduce misunderstandings between environment (P9)	Child and new care circle member (B17-B19)	Losing privacy (P8)	6
Alternative, continuous and self-assessment (A29, A34)	Reduce cost, provides more opportunity for improvement (P7)	Child and new care circle member (B17-B19)	None	7

<i>Artefact</i> features and capabilities under consideration	Related <i>Purpose</i>	Potential <i>Beneficiaries</i>	Risks of increased costs or adverse consequences	Activity No.
Accessible system (A35-A37)	To be finalised (inclusive of users who may have special needs)	Child and new care circle member (B17-B19)	None	8

The need for three existing features (*artefact*) was strengthened, two of them with additional *purposes*, five new *artefact* features with *purposes*. Two additional risks relating to incorrect information and incorrect advice were also identified.

5.7. Summary of Iteration 2

The aims of this iteration were to explore the viability of a social support and information system, to satisfy the needs identified by Activities 1-4 in Chapter 2 and potentially improve the current situation and if such a system was desirable to the potential *beneficiaries*.

The purpose of Activity 5 was to understand new STSs with the potential to design a solution in the form of a social network with information resources. Activity 6 emphasised the importance of reducing misunderstanding between families and schools. It also built on the findings of Activity 5 by showing there was a requirement to provide care circle members with continuous training and to enable them to carry out school-related activities at home. Activity 7 was conducted to improve understanding of present communication patterns, ideal communication methods and professional care circle members' attitudes towards the envisaged solution. Activity 8 applied the findings from previous activities to the CAT model to understand the requirements of the potential *artefact* better. The findings from Activities 5-8 were listed at the end of each of the activities against *beneficiaries*, *artefacts* and *purpose*.

5.8. Reflection on Iteration 2

Both primary and secondary research activities were included in this phase of RtD. *Design arenas* were addressed in parallel throughout the four activities.

5.8.1. Order of Activities 5-8

In reality, Activity 5 started before Activity 4 but they were both recorded at the same time. Of the activities so far recorded, Activity 5 took the longest to complete due to amount and breadth of information that had to be analysed. Activity 8 was also published as a conference paper (George *et al.*, 2010).

The investigation into STS in Activity 5 was between June 2008 and May 2009. Activity 6 was conducted in October 2009 over about an hour and Activity 7 was conducted on the 21st July 2009. The STS using *Ning* was attempted in September 2009. Activity 8 was the first to be carried out in November 2009 (Table 5.5).

Table 5.4 - Order of Activities

Chapter 5: Activities 5-8	
<i>June 2008</i>	Activity 5: New Socio-Tech started
<i>November 2008</i>	Activity 8: CAT model exploration;
<i>May 2009</i>	End of Activity 5: New Socio-tech
<i>July 2009</i>	Activity 7: 21st July 2009 Interviews
<i>August 2009</i>	Design Social network sketches
<i>September 2009</i>	Activity 8: Built - <i>Ning</i>
<i>October 2009</i>	Activity 6: Discussion
<i>November 2009</i>	Activity 8: CAT model application

The activities were built on and written up in Chapter 5 in an order that was different to the order in which they were carried out. This shows that even when activities are conducted sequentially, they can be recorded and reflected on in a non-sequential manner as the research leads, in a way that is more beneficial to the research.

5.8.2. Scope of Iteration 2

Chapter 5 focused on *beneficiaries*, their needs and wants for *artefact*, and *purpose* (Figure 5.2). In addition, existing artefacts were also evaluated against the purpose and artefact features identified. Further, the STS concept was also explored. STS by their very nature focus on beneficiaries, but also explore a range of artefact options and features. The CAT model systematised findings on purpose, beneficiaries and artefacts for the design solution and evaluated the potential of existing solutions. The findings from this iteration are fed into the next iteration, recorded in Chapter 6.

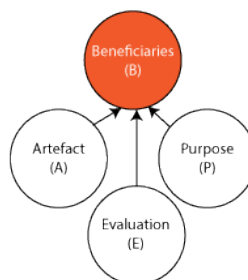


Figure 5.2 - Most Abstract Design Situation (MADS) of Chapter 5

Similar to Activities 0-4, the design moves for activities in this iteration were different to what was expected. Activity 5, a literature review, was expected to produce information on potential artefact options and additional purposes. The findings revealed additional beneficiaries, yet fewer artefacts and two potential purposes than expected were identified (Figure 5.3). The discussion in Activity 6 produced information on artefacts as anticipated, and more information than was anticipated on purpose and beneficiaries (Figure 5.4).

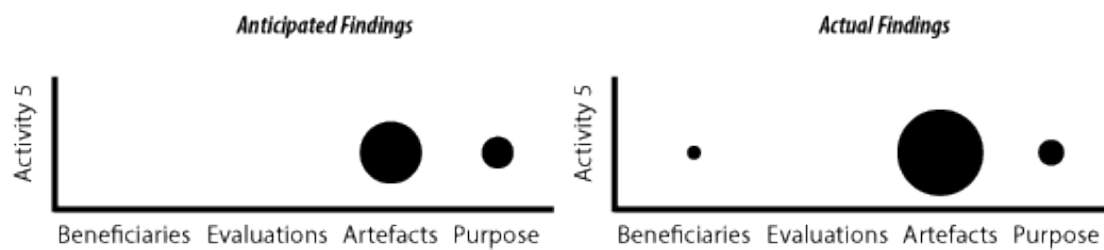


Figure 5.3- Proportional Abstract Design Situation (PADS) of Activity 5 – STS Study

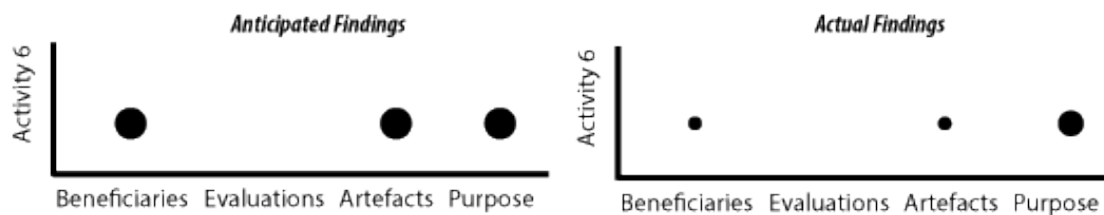


Figure 5.4 - Proportional Abstract Design Situation (PADS) of Activity 6 – Discussion

The semi-structured interviews in Activity 7 produced information on artefacts as anticipated and less information than was anticipated on purpose and beneficiaries (Figure 5.5). The CAT model in Activity 8 was only anticipated to be an integrative tool but also explored beneficiaries, purpose and existing artefacts (Figure 5.6). It also resulted in innovatively extending the CAT model as envisaged by Hersch and Johnson (2009b). These differences are shown in Figures 5.3-5.6.

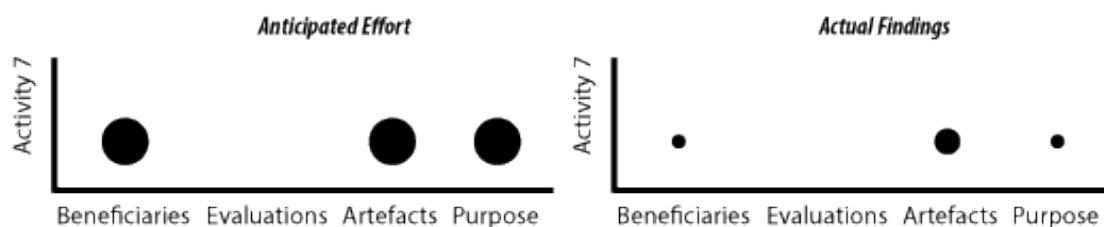


Figure 5.5 - Proportional Abstract Design Situation (PADS) of Activity 7 - Interviews

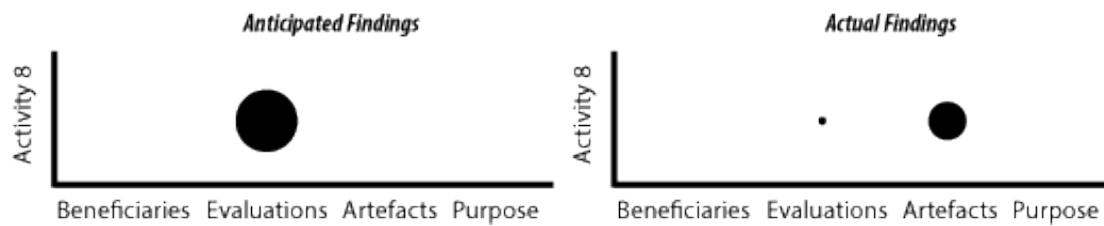


Figure 5.6 - Proportional Abstract Design Situation (PADS) of Activity 8 – CAT Model

5.8.3. Progress in Iteration 2

The exploration of STSs in Activity 5 indicated that an ICF based holistic approach to disability was indeed possible within a STS where technology can be used to support the social setting. The care circle member from a family in Activity 6 confirmed the appropriateness of a social and information support system with networking opportunities within and between care circles. This activity also demonstrated that cross environment communication was important. The professional carers interviewed in Activity 7 were also receptive towards such a system. Activity 8 organised the findings within a CAT model and emphasised the importance of such a system being compliant of accessibility requirements and being inclusive.

Iteration 1 provided a list of up to 20 care circle roles. Activity 6 provided the first exposure to a family member who provided an insight into her usage context and potential for a social and information support system with networking opportunities. This improved the understanding of care circle members. This understanding of beneficiaries was further improved in Activity 7 by the exploration of the idea for potential solution with professional members of the care circle.

This iteration closed having established the need for a social and information support system with networking opportunities. Having studied STSs in Activity 5, this was enhanced to the need for an STS around an integrated communication system that was responsive to care circle members and was inclusive of disabled users.

The design progress made in this iteration shifted the position on purpose to be more holistic, being embedded across different environments to improve quality of life of disabled individuals.

The conclusions reached from this iteration are as follows:

- A STS has potential to meet the needs identified in the previous and current iteration;
- Care circle members from both family and professional environments are positively receptive to such a system;
- The system needs to be fully accessible.

This iteration aimed at improving understanding of *purpose* and explored the potential of an envisaged *artefact*. However, it increased the understanding of *beneficiaries* and a STS as an *artefact* in its usage contexts and the connections between these design arenas. The shifts in design arenas are summarised in Table 5.5.

Table 5.5 – Iteration Shift for Chapter 5

	<i>From</i>	<i>To</i>
<i>Beneficiaries</i>	Current understanding of care circles	Improved understanding of family and professional roles and confirmed their response to a potential social tool.
<i>Evaluation</i>	Not known.	Explored potential for existing social network and building from an existing framework.
<i>Artefacts</i>	Comprehensive multimodal platform with social networking tools	Integrated communication within a social support and information system.
<i>Purpose</i>	Current target benefits and relevant possible costs and aversions	More holistic understanding of worth for care circles. Being sensitive to the response of beneficiaries to the proposed system.

5.8.4. Resource Function Analysis

The functions of the resources used in Activities 5-8 were generally same as expected (Table 5.6). However, Activity 7 was also *protective* and Activity 8, which was expected would simply organise (*integrative, expressive*) the existing findings also enabled exploration of further information, which made it *informative* and *inquisitive* as it prompted several new ideas.

Table 5.6 – Realities of Resource Functions in Iteration 2

Activity	Resource	Achieved Functions
Activity 5	Desk/Secondary research	Ameliorative, Informative
Activity 6	Discussion	Informative, Inquisitive, Invigorative, Performative, Protective
Activity 7	Interviews	Directive, Expressive, Informative, Inquisitive, Invigorative, Performative, Protective
Activity 8	CAT model	Expressive, Integrative, Informative, Inquisitive, Invigorative, Protective
Cumulative Function		Invigorative

Activities 5-8 involved a family member and professional carers who were collectively receptive of a website with social networking capabilities as design solution. These findings now needed to be confirmed by a wider group of participants, which makes Iteration 2 cumulatively *invigorative*.

The above activities generated sufficient information to make the design situation sufficiently concrete to move it to the next step.

5.9. Next Iteration

This chapter explored the possibility of a social support system within the ICF context of a STS via a web platform with social networking and information capabilities. A summary of each of the activities recorded in this chapter listed any new findings by design arena. Activity 8 included the CAT model that *expressed* the current situation with and without the use of an online social support system. However, the *artefact* features, *purposes* and *beneficiaries* need confirmation by a wider group of users prior to being developed as an *artefact*.

This iteration achieved positive shifts in the understanding of *beneficiaries*, *artefact* requirements and *purpose*. The focus of the next iteration is to design, pilot and field a questionnaire. While this next iteration is to be led by evaluation, findings are anticipated in all *design arenas* and therefore the same weighting was given to all.

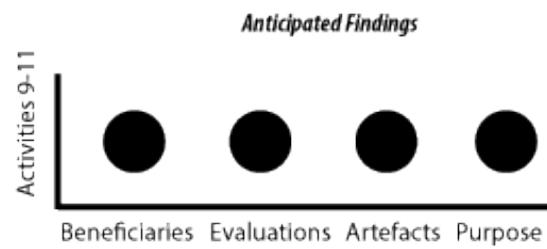


Figure 5.7 - Anticipated Proportional Abstract Design (PADS) Situation for Iteration 3

Based on the information identified and analysed in this chapter, the next chapter aims to shift the design arenas as per Table 5.7.

Table 5.7– Anticipated Iteration Shift for Chapter 6

	<i>From</i>	<i>To</i>
<i>Beneficiaries</i>	Improved understanding of family and professional roles and confirmed their response to a potential social tool.	Involvement of balance of professional and carer roles
<i>Evaluation</i>	Explored potential for existing social network and building from an existing framework.	Confirm existing information by way of survey and find any new information.
<i>Artefacts</i>	Integrated communication within a social support and information system.	Adding more detail to the requirements for the social networking system.
<i>Purpose</i>	More holistic understanding of worth for care circles. Being sensitive to values of beneficiaries.	Confirming the potential of worth centred user needs for the artefact.

Chapter 6 – Iteration 3: Confirming Requirements of a Probable Artefact

Chapters 4 and 5 focused on two different possible *artefacts*. Chapter 4 recorded five activities that were effective in moving towards a better understanding of the problem. *Beneficiaries* and *purpose* identified in the research problem were connected to *artefact* features in the Worth Integration Table. Chapter 5 recorded four further activities and analysed findings based on design arenas focused on improvements for care circle members, who are the stakeholders in this study. The design connections identified in Chapter 5 were also captured in a Worth Integration Table. Chapter 5 concluded by identifying a social support system within a Socio-Technical System (STS). The design and suitability of such a social support system needs to be evaluated prior to implementation.

The next step in Chapter 6 is to empirically strengthen the confidence in the requirements for the probable *artefact* scoped across Chapters 4 and 5.

This chapter starts by presenting the current situation with the increased benefits and reduced costs that are anticipated with the envisaged artefact. In order to check technical and value assumptions from the activities so far, the findings from Activities 1-8 were expressed in a Worth Sketch that was followed by Worth Shift and Artefact Connection Tables enabled corroboration via a questionnaire. This led to identifying where gaps in knowledge appeared and assumptions that needed confirming. Based on this, the Worth Sketch was revised, and this informed the design of a questionnaire that was piloted and fielded, and the data from it was analysed to gather the information for the design of the artefact.

As with any design in support of complex social settings, there were many research challenges:

- It is not possible assume that care circle members, especially the professionals, would spend more time than they normally would on disabled individual's needs;

- The ‘technical’ involvement may be considered additional work for users not used to social networks, i.e., they need to devote effort to accessing and learning a new social network;
- The artefact may find it difficult to accommodate different interaction requirements with different membership, environments and support needs for each care circle.

There were also design challenges:

- Responding to corroborated (de)motivations of care circle members where they may have already been part of previous research activities but without any direct benefits;
- Making social support systems that are accessible to the care circle members;
- Getting a broad range of members of the care circle adequately involved and defining the extent to which they will be involved.

The hope is that care circle members who need to build a community would like to ‘invest’ in being part of a STS.

6.1. Worth Sketch Version 1

During the interviews and observations, the participants indicated that they do their best in the current situation, but indicated that their ideal aim would be to improve the capability of disabled individuals by timely and effective communication within their respective care circles.

This was visualised using Cockton’s (2008) Worth Sketches, (described in Chapter 2 (Section 2.3.3.5)). While a very simple means-end chain could include just means (features) and ends (benefits), Worth Maps have more complex means-end chains as they deconstruct artefact means into materials-features-qualities. Human means (experiences) involve features and/or qualities in ways that result in human ends (outcomes). Worth Sketches have all these elements but not the connections used in Worth Maps. In this research, Worth Sketches are sufficient to present the identified components as the connections are already presented using other integrative tools such as Worth Integration Tables 1 and 2 (Figure 4.1 and Figure 5.4).

The elements of the first version of the Worth Sketch (See Appendix C6 – Worth Sketch 1) were identified from Worth Integration Tables underpinned by the *purpose*, *artefacts* identified by and for *beneficiaries* in Activities 1-8.

Features and materials are neutral elements. Qualities, outcomes and experiences can be positive (worthwhile) or negative (adverse). Based on the artefact features and qualities identified over Activities 1-8, worthwhile and adverse outcomes together with experience, qualities, features were identified. Materials were not decided at this stage. The identified components were also not linked at this point.

6.2. Worth Shift Tables

The Worth Sketch incorporated worthwhile outcomes, worthwhile experience qualities, features, materials, adverse experience and adverse outcomes. This Worth Sketch maps out a snap shot of what is positive and negative at a certain point in time in the research process. It is also used to indicate how qualities / features / materials or artefacts could increase benefits and reduce costs. However, it does not recognise the shift in this worth that is anticipated by the artefact.

Worth Integration Tables, an original concept that listed and integrated options for *beneficiaries*, *evaluations*, *artefact* and *purpose* were presented at the end of Chapters 4 and 5. The Worth Shift tables in 6.1-6.3 are also an original concept from this research, where there is an explicit contrast between current and ideal situations. These tables organise information on the current and ideal situations identified through Activities 1-8, and prioritises the need for addressing each individual situation (Tables 6.1-6.3). The prioritisation is based on the impact of the proposed changes. The priorities are categorised into levels 1, 2 and 3 and the cost/aversion/lack/adverse outcome and benefits are marked for each item listed. They are prioritised based on what is perceived to have the most impact or benefits for care circle members.

Table 6.1 – Priority 1

Current	Ideal
Cannot participate in all meetings (cost)	Access to all information from meetings even <i>when they cannot personally attend</i>
Time and distance limitations (cost)	Being able to communicate from <i>anywhere with internet access.</i>
Need to organise meetings for professionals to show development of child (cost)	Should be able to <i>share</i> the current situation of child <i>immediately</i>
Annual assessment service provided (cost and lack)	<i>More frequent</i> assessment
Need to wait for the relevant professional to respond to queries (cost)	<i>Any available professional or parent</i> responding in a more timely manner to immediate needs
Child unable to communicate problem (a specific case where the professionals kept guessing what could possibly have gone wrong since child was unhappy all day) (adverse outcome)	A method of communication that would <i>immediately inform all</i> those involved of any recent current issues or concerns
One-sided uncoordinated decision making (adverse outcome)	Collective balanced co-ordinated decision making

Table 6.2 – Priority 2

Current	Ideal
Multiple methods of communication – independently accessed and un-coordinated (cost)	Multiple methods of communication accessed via a <i>single platform</i> , with <i>co-ordination</i> through cross referencing etc.
Dependent on professionals (cost)	<i>Dependent on social support group</i>
No regular contact with other families in similar situations (lack)	<i>More timely communication</i> with other families in similar situations
Major time investment from professionals (cost)	<i>More manageable time</i> investment from professionals
Children are treated as one of many ‘patients’ or isolated (aversion)	Children could <i>be part of a community</i> of care circles, children from mainstream and special schools, support groups, etc.
Difficult to provide technical support on AT devices (lack)	<i>More support from social network</i> users
Unstructured communication (aversion)	<i>Persistent communication</i>
Financial restrictions limit the regular involvement of professionals (cost)	Reduced <i>impact of financial</i> constraints
Therapy and help is offered onsite (location) only (cost)	<i>Online</i> video-based assessment, therapy, support and guidance could also <i>be made available</i> to families

Table 6.3 – Priority 3

Current	Ideal
Need to search various website and databases to find relevant information on schools and opportunities (cost)	Most support information found in a <i>single environment</i>
Information pack sent out and returned (cost)	No reported problems but <i>could also be made available online</i>
Limited and uneven access to social networks of unknown quality and trustworthiness (aversion and cost)	<i>Focused, targeted access</i> to social networks of known quality and trustworthiness

Worth Shift Tables are a resource that is initially *expressive* and *integrative* of existing findings. However, this is also *ameliorative* and *directive* in providing targets for each of the situations by providing an ideal target to achieve. The prioritisation is also *adumbrative*.

6.3. Artefact Connection Tables

The proposed ideas for an ideal situation were predominantly what professionals believed that parents would like, apart from ideas from two parents (Activity 4: autobiographical study and Activity 6: discussion with family care circle member). An online social support system could potentially include all of the above ideal features associated with worth, but it was important to establish that this does not lose the positive features in the current situation or introduce new problems. It was also essential to confirm if the suggestions were acceptable to the majority of those involved in the care of individuals.

6.3.1. Risks in Improving Benefits and Reducing Assumed Costs

While Activities 6 and 7 (second interview at the assessment centre) confirmed the interest of a few potential *beneficiaries*, it was important to find out if a wider group of potential users would accept a social support systems as a solution, their attitude to the proposed solution, and their expected usage patterns and frequency. If the overall responses are positive, it is important to identify what options and opportunities they would like in the system. If they do not like the solution, the task should be to then attempt to find other solutions that they would prefer.

Firstly, the target audience needed to be clearly defined and understood. The involvement of the care circle members with the disabled individual (for example if they lived with the individual, or spent time with the individual on a regular basis, or were involved professionally), could influence the purpose of communication using a virtual environment. Their IT skills could influence how comfortable they are with IT based solutions and the need to rely on IT. The capabilities of members of the care circles could have implications on the support required in using the artefact. The existing methods of communication used by members of care circles need to be absorbed into the design solution to maintain their existing benefits, thereby contributing to a worthwhile social support system.

Secondly, to assist in the identification of care circle priorities, the strengths and weaknesses of the current situation should also be assessed. This was to help to identify the most crucial needs of the care circles.

If the proposed design solution will genuinely improve the current situation, the benefits of the existing situation should be improved further and any current costs or aversions should be reduced. The current situation should not deteriorate either.

The following sections further consolidate the findings from existing activities and connect both new benefits and existing costs and risks to the potential features of the *artefact*.

6.3.2. Connecting Benefits and Aversions to Artefact Features

Artefact Connection Tables (Tables 6.4-6.5) are a connecting tool between *beneficiaries* and *artefact*. These are similar to the *feature-benefit* tables that are common in business plans (Grikscheit, *et al.*, 1993) and are used to operationalise Needs Satisfaction theory. The feature-benefit table maps the needs and wants (benefits) of the business client against the feature of what is being sold. *Artefact Connection* tables visualise how the *beneficiaries* are connected to *artefact* features and their *purpose* by identifying current and ideal situations. In order to shift the current situations towards ideal situations, either benefits need to be improved or aversions need to be reduced. In order to design an artefact that meets the needs of

both beneficiaries and purpose, a potential feature that could deliver for each opportunity is identified using findings from Activities 1-7.

Table 6.4 – Artefact Connection Table 1

Improved Benefits for <i>Beneficiaries</i>	Potential <i>artefact</i> Features
No additional time needed for full disability assessments	Progressive assessment uploads
Less challenging to arrange times for all <i>care circle members</i>	Synchronous and asynchronous usage, possible video chat
More time spent supporting <i>disabled individual</i>	Single point of contact for communication and reliable information
Inclusive participation of individuals in <i>care circle</i>	Forum/discussion restricted to Care Circle members
Support from <i>all members</i> of network	Open forum for all members of the social network
Open <i>peer</i> support for family members	Open forum for all members of the social network
More visual interaction for <i>care circle members</i>	Ability to post still and moving images, possible video chat
Dynamic network dialogue for <i>care circle members</i>	Forums and discussions
Progressive evaluations for <i>disabled individual</i>	Continuous discussion on progress of child.
Happier environments for <i>disabled individual</i>	Complete support group and reliable information
Better education for <i>disabled individual</i>	Share support material and support innovations

The following table connects costs to artefact features.

Table 6.5 – Artefact Connection Table 2

Reduced Costs/Aversions for <i>Beneficiaries</i>	Potential <i>artefact</i> Features
Reduce/remove time taken to travel for <i>care circle members</i> for meetings	Synchronous and asynchronous usage
Easier to arrange meetings between <i>care circle members</i>	Sharing calendars
Time spent making arrangements to support child for <i>care circle members</i>	Sharing calendars and discussions
<i>Many care circle</i> members cannot participate in meetings	Synchronous and asynchronous participation
Support dependent on <i>professionals</i>	Forums open to all users of the social network, support not wholly dependent on professionals
Selected examples of peer support (professionals referring to specific parents of children) for <i>family members</i>	Choice of restricted or open forums

Reduced Costs/Aversions for <i>Beneficiaries</i>	Potential <i>artefact</i> Features
Mainly text based or phone based conversations between <i>care circle members</i>	Ability to post still and moving images, possible video chat

These Artefact Connection Tables that map reduction or costs and increment of benefits are an original concept demonstrated in this research where costs/aversions and benefits for beneficiaries are mapped against artefact features and are measurable. This is further original as this is the first time a business model is being used in the context of HCI and RtD.

6.3.3. Assumptions and Missing Information

Worth Shift tables (Tables 6.1-6.3) prioritised current to ideal Worth Shifts for *beneficiaries* and Worth Tables 1-2 (Tables 6.4-6.5) mapped *artefact* features against Table 1 for improved benefits and Table 2 for reduced costs and aversion by potential *artefact*.

The Worth Shift tables and Artefact Connection Tables (Tables 6.1-6.5) were examined to identify assumptions that required confirmation and missing information. These are listed in Tables 6.6 and 6.7. These confirmations and additional information would later be sought through a questionnaire.

The alphanumeric characters from Tables 6.6 and 6.7 provide a key to identify assumptions and confirmations in the questionnaire and subsequent worth sketches.

Table 6.6 – Incomplete or Missing Information from Findings

Incomplete or Missing information
A. What is good about the current situation
B. List of what is not ideal about the current information
C. List of what could be better about the current information
D. What methods of communication are used, and which are preferred, and when
E. Opinion on Social networking
F. Demographics, including IT access, of care circle

Table 6.7 - Assumptions from Findings

Assumptions to be Confirmed	Confirm by Gathering Information on (letters refer to Table 6.7)
<p>1. The situation is not ideal because:</p> <ul style="list-style-type: none"> a. Time and distance limitations prevent all members of care circle from participating in all meetings; b. Only dedicated professionals can answer queries even when peers/other care circle members might know the answer but, need to wait. But, this is a major time and financial investment from professionals; c. Assessment is usually only once a year; d. Child may be unable to communicate problems between professionals and family members; e. Multiple methods of communication are independently accessed, unstructured and uncoordinated; f. Children are treated as one of many ‘patients’ or in isolation; g. It is impossible for assessment centres to provide technical support on AT devices; h. Therapy and help is offered onsite (location) only; i. Need to search various website and databases to find relevant information on schools and opportunities and still not have reliable answers; j. Information pack is obtained only in hard copy; 	A, B, C
2. There is a need for frequent communication within care circles	D
3. Care circle members own a computer and access the internet	F
4. That social networking is a viable solution	A, E, F
5. Care circle membership is between 2-7	F
6. Age of Cared for is 0-16	F

This analysis was used to produce a further version (Version 2) of the Worth Sketch (Version 2 - Figure 6.1 – in Section 6.5).

6.4. Worth Sketch Version 2

Assumptions with reference number 1-6 and letters a.-j. in the first column of Table 6.7 were mapped onto elements of Worth Sketch Version 2 (see Figure 6.1 below) against its elements. All of these lower case letters had corresponding upper case letters A-F that are referred to as Incomplete or Missing Information in Table 6.6.

In the process, the Artefact Connection Tables (Tables 6.4-6.5) containing the connection between *beneficiaries* and *purpose* and thereafter the connection between *purpose* and *artefacts* were used to fill any gaps in the Worth Sketch.

The elements in Worth Sketch Version 1 were retained but expanded upon. The first Worth Sketch started with four worthwhile outcomes and this list has been extended to ten in Worth Sketch Version 2. The number of worthwhile experiences also expanded from four to ten. The qualities required of the potential solution expanded from three to seven. Based on findings from Activity 5 (STSs) the features increased from three to nine and the materials necessary for this were identified to be eight. The current adverse experiences expanded from five to ten and the adverse outcomes increased from three to nine.

The next stage in the process was to recruit participants outside the Centre who would provide a more balanced and comprehensive view of the needs of potential users. Data had to be systematically gathered from these participants to guide development of a more suitable design solution. This further research was *inquisitive* and *informative*, in that it aimed to provide more data for the design research.

Worthwhile Outcome	a. More care circle members can participate	b. Improve personal, social and environmental factors	c. Appropriate and timely support	d.g. Improved communication	e. Better informed life style support	f. Don't feel isolated	g. Better, flexible AT support	h. More frequent and accurate assessments	j. Save time	j. Improved access
Worthwhile Experience	a. Manageable schedules	b.e. Dependable knowledgebase	c. Satisfactory Service	d. Confident communication	e. Reduced stress	f. Motivated	g. Moral Support	h. Reduce time and travel demands	i. Empathetic environment	j. Convenient
Qualities	a. Flexibility of time and distance	b.c.g.i. Effective & efficient	d. Accurate & reliable	e.g.i. Informative & helpful.	f.g. Caring, encouraging, motivating	h. More frequent help	j. Technically accessible			
Features	a. Live & Synchronous participation	b. Platform where any care circle member could respond	c. Frequent and continuous assessment	d. Professionals and fairly regular communication.	e.i. Support services	f. Know who is the individual's care circle	g. AT support from developer and peers	h. Video and/or self-help therapy	j. Available for download	
Materials	a.g. Chat, discussion boards	b.g. Wall posts, forums	c.h. Online assessment forms, videos	d. Alerts, personal messages, status update	e.g.i. Resource sharing	f. Visual overview of care circle members	h. Video chat	j. Multiple formats		
Adverse Experience	a. Fewer decision Makers	b. Support and advice delay	c. Assessments only annual	d. Poor professionals-family communication	e. Too many methods of communication	f. Feel isolated	g. Insufficient tech support	h. Poor off-site support	i. Inconsistent, unreliable or no information	j. Inflexible solutions
Adverse Outcomes	a. g. AT in the cupboard	b. c.h. Poor quality of life for child	c. h.i. Delayed progress of individual	d.i. Unhappy or confused individual	e. i. Lack of information	f. h.i. Unhappy family	a. Biased decisions	e.i. Waste time		j. Incompatible solutions

- a. Time and distance limitations prevent all members of care circle from participating in all meetings;
b. Only dedicated professionals can answer queries even when peers. Other care circle members might know the answer but need to wait. But, this is a major time and financial investment from professionals;
c. Assessment is usually only once a year;
d. Child may be unable to communicate problems between professionals and family members;
e. Multiple methods of communication are independently accessed, unstructured and uncoordinated;
f. Children are treated as one of many 'patients' or in isolation;
g. It is impossible for assessment centres to provide technical support on AT devices;
h. Therapy and help is offered onsite (location) only;
i. Need to search various websites and databases to find relevant information on schools and opportunities and still not have reliable answers;
j. Information pack is obtained only in hard copy.

Figure 6.1- Worth Sketch Version 2

The remainder of this chapter reports how a questionnaire based survey was designed, piloted and fielded to confirm assumptions and find incomplete or missing information in the table.

6.5. Activity 9 - Questionnaire Design

Chapters 4 and 5 reported on findings from contextual interviews and associated activities that were conducted to establish *purpose*, *beneficiaries* and features for the potential *artefact*. The findings from these activities required systematic confirmation from further participants and triangulated against the field data. To do this, different data collection methods were considered. Information had to be gathered from further members of care circles and other organisations with potentially different needs. Consequently, questionnaire based survey was chosen to obtain this data.

The purpose of the questionnaire was to evaluate if a social support system could function as an effective means to address some of the current challenges for care circles of individuals with disabilities. The goal of the questionnaire was to corroborate assumptions about, and understandings of, the current and ideal situations arising from the Worth Shift tables. This questionnaire would help to identify whether the current situation could be improved by using a single platform to achieve as many as possible of the pre-requisites of an ideal situation.

Various possible methods were explored for the survey. Questionnaires and interviews were considered based on the type of information required and obtaining unbiased information from members of care circles. The questions needed to be systematically mapped against the information already identified as incomplete or missing. The findings would have to be summarised and analysed.

As a result, two versions of a questionnaire were designed, one for professional and another for personal care circle members to be used both on paper and online. The questionnaire was completed by both professionals and personal care circle members, who had the option to complete the questionnaire face-to-face whenever possible or online. The questionnaires were designed to help to identify the needs of family members and professionals involved in the care of an individual with special needs and to confirm the assumptions of the research. The questionnaire was also intended

to help to estimate the possible costs and potential benefits of the design solution and to elicit users' response to the proposed solution. The responses to the questionnaire were used to inform the development of the design solution and to evaluate its technical acceptability.

The data collected by the questionnaire included data on demographics and the behaviours of care circle members, such as computer and internet usage. This information was to be used to identify different user groups and their needs. In addition the questionnaire attempted to elicit evaluations of how well the existing requirements of care circle members were met and their opinions of the proposed design. Finally, the questionnaire also addressed what the participants would like in the proposed solution.

This information was later used to design Personas (Chapter 7) that guided development of the implemented artefact.

6.5.1. Method

A questionnaire was designed, indicating where necessary if the question was exclusively for family members or for professionals involved in care and decision making of the disabled individual. The questions collected information on logistics, current situation, ideal situation and the users' response to the proposed design solution (see Appendix C6 – Questionnaire Revisions).

Each question was written to either confirm an assumption or find information that was incomplete or missing, as in Tables 6.6-6.7 (A-F). In order to simplify the question and to provide some context for the response, an *Info* section has also been included before most questions. The details of the rationale for asking each question and the question itself are also set out below.

6.5.1.1. Question 1 – Age of person cared for

Rationale: Understanding variation within care circles is important to know if there are subgroups that differ in needs and resources (Missing Information F), for example in the type of educational needs or life skills that are required.

DEMOGRAPHICS (parents only)

Info: Depending on the age of your child, the communication purposes and needs will differ. To help us provide the most appropriate solution, please write the age of your child.

(1) Question: The age of my child is:

DEMOGRAPHICS (professionals only)

Info: Depending on the age of the children you work with, the communication purposes and needs will differ. To help us provide the most appropriate solution, please write the range of age of the children you work with.

(1) Questions: The age of children I work with range from to.....

6.5.1.2. Question 2 – Number of, and relationships between, care circle members

Rationale: Each care circle will differ in the involvement of the immediate family, extended family and professionals in the life of the person cared for. Each care circle member will also be involved in different ways and have different degrees of influence in the decision making. There may also be members of the care circle who families may not want to include in decision-making. For example, families may be reluctant to share all details with some care circle members like social workers, as this could make them appear to have children at risk, and not merely children with special needs (Missing Information F).

DEMOGRAPHICS (parents only)

Info: The progress of the child relies heavily on those who are involved in the regular decision making. They may include siblings, parents, grandparents, relatives or family friends.

(2.1) Question: The number of family members, relatives and friends who are involved with your child's progress:

(2.2) Question: Please list the relationships. e.g. Dad, aunt, grandmother, family-friend, etc.

DEMOGRAPHICS (professionals only)

Info: In addition to family members, you may also have professionals from various capacities involved in the decision making of a child's progress. This may also be at various frequencies.

(2.1) Question: The number of professionals who are involved with a single child's progress ranges from:to

(2.2) Question: Please list their roles. e.g. Speech therapist, carer, teaching assistant, etc.

6.5.1.3. Question 3 – Internet features currently used

Rationale: It was clear from preliminary research that most care circle members from the Centre referred to in Activities 1 and 7 are members of Google Groups. Further data on the general usage of media and the preferences of care circle members, would help to determine whether the care circle members would use web-based communication methods, and if they would understand familiar features of the internet (Missing Information F).

CURRENT SITUATION (Families and Professionals) - Demographics

(3) Question: Which of the following capabilities of the internet do you use?

Select from: I do not use the internet; E-mail; Chat (text or voice); Video messaging; Forums or Discussion groups; Blogs; Social networks; Other (specify).

6.5.1.4. Question 4 – Current methods of communication

Rationale: Based on the preliminary research, it was evident that numerous media were used to communicate within the care circle. When choosing a design solution to enable better communication, it is important to identify care circle members'

preferred methods of communication, and how this may depend on the urgency of the situation (Missing Information D).

The wording of the question differs for families' and professionals' questions. For example, while the family members' question includes the phrases '*schools and support organisations*' and '*schools or support organisations for your child*', the corresponding version for professionals reads as '*parents, schools and support organisations*' and '*family members involved*'. There are no differences in the available responses. In each case respondents entered their responses via a Likert matrix (Trochim, 2006).

CURRENT SITUATION (Parents)

Info: You may be using various media to communicate with schools and support organisations. This could give you the needed flexibility and at the same time complicate things when all those you would like to consult are unavailable or have to duplicate information when using various media.

Question 4: Please mark in each row below how likely you would be to use the following methods for communication with schools or support organisations for your child? *Select from:*

Telephone; Email; Letter; Child's homework book; Periodic meetings or events other than annual review; Annual reviews; Onsite training; Social networks; Online forums and groups; Other (specify) and columns for Very likely; Likely; Neutral; Unlikely; Very unlikely.

CURRENT SITUATION (Professionals)

Info: You may be using various media to communicate with parents, schools and support organisations. This could give you the needed flexibility and at the same time complicate things when all those you would like to consult are unavailable or have to duplicate information when using various media.

Question 4: Please mark in each row below how likely you would be to use the following methods for communication with the family members involved? *Select from:* Telephone; Email; Letter; Child's homework book; Periodic meetings or events other than annual review; Annual reviews; Onsite training; Social networks; Online forums and groups; Other (specify) plus columns for Very likely; Likely; Neutral; Unlikely; Very unlikely.

6.5.1.5. Question 5 – Preferred method of communication

Rationale: In order to prioritise their media preference, the following question was asked with the option to select only one answer (Missing Information D).

CURRENT SITUATION (Families and Professionals) - Receptiveness

Info: When you communicate urgently with those involved with your child, you may have a preferred method of communication used in practice.

Question 5: In case of an immediate need for the child, which method of communication would be your first approach? Select one answer from: Telephone; Email; Write a note on child's homework book; Wait for the next event; Book onsite training; Wait for the annual reviews; Discuss it online; Search for a solution online and Other (specify).

6.5.1.6. Question 6 – Importance of peer support

Rationale: There was evidence of families and associated professionals placing high value on networking with peers in order to share experiences, ideas and problems. At the same time, there are also family members who prefer to accept the condition of the individual with special needs and take a more pragmatic approach, and do not consider peer networking as important. It was also identified during the primary research that time and distance factors were insurmountable challenges in peer networking. If this need was to be met, the demand needed to be identified clearly. A likert scale was used to elicit the priority of need (Missing Information from A and B).

CURRENT SITUATION (Families and Professionals)

Info: Peer networking with other families or professionals may be beneficial for both practical and emotional support.

Question 6: How important do you consider communicating with other care circles?

One response to be from Likert scale: Very important 5; Important 4; Neutral 3; Not important 2 and Not important at all 1.

6.5.1.7. Question 7 – Quality of current communication

Rationale: The responsibility for providing the child with suitable assistance and guidance lies with the care circle. The expectations of care circle members needed to be identified and the current situation needed to be assessed to determine if they were currently being met, and if so, how. It would also be useful to gain some insight into how satisfied care circles members are with the current situation. This would help to understand what the proposed design solution could contribute. A likert scale was used to identify the satisfaction (Missing Information A and B).

CURRENT SITUATION (Families and Professionals)

Info: With the variety of communication modes at your disposal, you may find they are either used to it highest potential or inefficiently.

Question 7: How would you grade the current modes of communication with professionals and family members involved in the care of your child?

One response to be from Likert scale: Very good 1; Good 2; Average 3; Poor 4 and Very Poor 5.

6.5.1.8. Question 8 – Characteristics of current communication

Rationale: The strengths and weakness of current communication methods needed to be identified so that strengths could be maintained and weaknesses could be addressed.

The responses to this question were drawn from Activities 6 and 7. Any findings were to be incorporated into the requirements of user experience of the artefact (Missing information B and C).

CURRENT SITUATION (Families and Professionals)

Info: In assessing the current situation with communication options, there may be varied opinions on the various factors that make communication effective.

Question 8: How would you rate the following qualities regarding the current communication options regarding your child? Likert Matrix with rows for Timely; Reluctant; Helpful; Flexibility of alternatives; Regular; Empathetic; Ambiguous; Abrupt; Patronising and Other (specify) and columns for Strongly Agree; Agree; Neutral; Disagree; Strongly Disagree.

6.5.1.9. Questions 9 and 10 – Qualities that should not change and need improving

Rationale: It was important that the design solution should maintain what works well in the current situation. At the same time, it needs to improve communication where users did not feel it was working well enough. In order to identify what should be retained and the important issues to be dealt with, the following questions were asked.

(Families and Professionals)

Question 9: From the above (Question 8) please list the 2-3 qualities you would like to keep at least as good as they are currently.

(Families and Professionals)

Question 10: From the above (Question 8) please list the 2-3 most important issues on communication quality that you would like dealt in order of priority.

6.5.1.10. Question 11 – Special needs of care circle members

Rationale: It was also essential to be sensitive to the concerns of families and associated professionals, who themselves may have disabilities (Missing Information C).

CURRENT SITUATION (Families)-Demographics

Info: There may be family members who wish to participate in the discussions and decision-making regarding a child, but are unable to do so for various reasons.

Question 11: Is there any special need of **the family member** that makes it challenging in participating in the decision making of a child's progress?

Select one or more from: Language limitations of family members; Motor or Physical disabilities of family members; Learning or Cognitive disabilities of family members; Computer competency challenges of family members; Do not have internet connection at home and/or work and Other (specify).

6.5.1.11. Question 12 – Internet usage frequency

Rationale: In order to assess the feasibility of a social network as a design solution and judge how frequency of potential online activities using the network it was necessary to determine how often members of the care circle currently use the Internet.

CURRENT SITUATION (Families and Professionals) – Demographics (Missing Information F)

Question 12: How frequently do you access the Internet? Likert from: Much of the day 1; Several times a day 2; Few times a day 3; Once a day 4; Every few days 5; Once a week 6; Few times a month 7; Once a month 8; Several times a year 9 and Almost never 10.

6.5.1.12. Question 13 – Preference for off the record communication

Rationale: Care circle members may be used to having off the record conversations and are not comfortable with putting things in writing (Activity 6). If so, it could be beneficial to introduce these care circle members to private message features, and potentially build some kind of ability to have ‘off the record conversations’ within the social network (Missing Information D).

CURRENT SITUATION (Families and Professionals) - Opinion

Info: There may be times when you feel that verbal communication is preferred over written ones that go on record depending on the nature of the matter.

Question 13: How important is it for you to have off the record conversations about your child? *Select one from:* Very, it is important to be honest; Can be useful, good to have them; No, everything should be on record and Other (specify).

6.5.1.13. Questions 14 and 15 – Potential topics and features for Social Network

Rationale: If the design solution is to function as a knowledge base and hold reliable information, the type of information care circle members looked for and would discuss on a social network needs to be understood. The type of features they might find beneficial also need to be identified (Missing Information E).

IDEAL SITUATION (Families and Professionals)-Opinion

Info: online social media could potentially offer the following solutions in a single website.

Question 14: Which of the following subjects do you discuss with members of the care circle?

Select from: Education; Entertainment; Assistive technology; Therapy; Assessments; Care & Hygiene and Other (specify).

The list of responses was obtained from the discussion reported in Chapter 5, Activity 6.

IDEAL SITUATION (Families and Professionals)-Opinion

Info: online social media could potentially offer the following solutions in a single website.

Question 15: Which of the following capabilities would you like the website to have? Select from: Progress updates for/on your child; Feedback on queries about your child; Follow up online assessments; Funding assistance; Technical support for assistive technologies; Should be able to view previous records; Option to choose the information to be shared with each member of care circle; Calendar; Audio/Video chats; Forums or discussions; Being able to print copies of discussions; All of the above; None and Other (specify).

6.5.1.14. Question 16 – Concerns about Social Network

Rationale: In order to understand the challenges and the current needs that the proposed design solution should address, it was important to understand the target users' views and attitudes towards this concept. It was also important to understand the privacy and security concerns of potential users. (Missing Information E)

IDEAL SITUATION (Families and Professionals)-OPINION/NEGATIVE

Info: If the proposed website was to be a form of social network (such as Facebook, Bebo, LinkedIn, etc.) but specific to support your child's development, you may have various opinions and concerns.

Question 16: What concerns would you have if an online network was launched to address the needs of communication? Select from: None; Privacy and Security; Timeliness and reliability of response; Time demands for participation and use and Other (specify).

6.5.1.15. Questions 17 – 18 – Future participation

Rationale: It was important to know if participants would be interested in this research once an artefact was developed.

IDEAL SITUATION (Families and Professionals)

Info: We are currently investigating the possibility of a social network that hopes to improve the current communication and networking strategies for children.

Question 17: Would you be interested in supporting this investigation by evaluating the interface in development at various stages? It would take approximately three 45 minute sessions over a year. Select Yes or No.

Question 18: If yes, please provide your contact details, Name and
Email or Postal address.

6.5.2. Summary

The outcomes of this design activity were the two versions of the questionnaires, one for the family members and the other for professionals. Mapping the assumptions and missing information to the questions was intended to help with mapping responses.

This activity was primarily expected to be *expressive* by organising the questions in a way that would *direct* the way the findings could tie in with the purpose of this iteration and support firmer guidelines for the development of the *artefact*. The rationale for asking each of the questions also made this activity *protective* as assumptions are verified and missing information is gathered.

This activity organised the existing information and produces a design resource for *evaluation* of assumptions and identifying missing information. Therefore, this activity did not identify any new *purpose*, *beneficiaries* or *artefact features*.

6.6. Activity 10 - Questionnaire Piloting

Prior to using the questionnaire as a tool, it had to be trialled with a smaller sample of participants.

6.6.1. Participants

The questionnaire was piloted with four participants who were members of the family of individuals with motor impairment.

Table 6.8 - Profile of Users

Participant	Care capacity
PP1	Sister
PP2	Mother
PP3	Sister
PP4	Father

6.6.2. Method

Paper based questionnaires were given priority since this provided opportunities for discussion at the point of contact. On one occasion, the questionnaire was provided in electronic format.

6.6.3. Findings

The piloting was at times complemented by lively discussions and suggestions. Some comments were generally about the questionnaire, while most were question specific.

PP4 suggested the statements leading into questions referred to as ‘Info’ should be visually different either in colour, italics or bold. As a response, these statements were italicised.

PP4 also suggested that clear instructions be given for each questions of what was expected. For example *circle*, *underline*, *tick*, etc.

All changes were applied to both family members and professionals’ versions of the questionnaire. The detailed comparison is in Appendix C6 – Questionnaire Revisions. A summary of changes are as follows:

- The introduction section was separated into purpose, explanation and definition of care circle as shown in Figure 6.2.

Your Opinion Counts.

Purpose: This survey is conducted to identify the best possible method to address the needs of the family members and professionals involved in the regular decision-makings for a child or adult with special needs.

There are eighteen questions and answering this questionnaire will take approximately 20 minutes to complete. All data will be used for the purpose of this research only. If you have any queries, you may contact Jennifer George on 079 3080 1010 or via email jenni26cg@gmail.com

Your time and effort is truly appreciated.

Definition: The team of people involved in the decision making during a child's development including family members, members of staff at school and medical practitioners are referred to as the care circle.

(1) Depending on the age of the child or adult you care for, the communication purposes and needs will differ. To help us provide the most appropriate solution, please write the age of the said child or adult. The age of child or adult I care for is:

Figure 6.2 - Questionnaire Introduction

- Question 1 was changed to refer to any carer and not just the parent.
- Question 2 had a sub-question 2.3 added to reflect the change to Question 1, and to also understand the relationship between the participant and individual they care for.
- Question 3 was rephrased to explicitly state features rather than capabilities of the Internet.
- Question 4 columns were changed to frequency from Likert Scale. This change also reflected in the change of Question 5.
- Questions 6, 7, 13, 14, 15 and 17 were edited to appear consistent with others by removing numbers, including response instructions and requiring an 'x' rather than circling. An addition definition for care circle was also included in Question 6.
- Some technical words were replaced with some generic words in Question 7, e.g 'communication mode' was replaced with 'ways of communication'.
- Question 8 responses were split into positive and negative aspects as new questions 8 and 10. Questions 9 and 10 were placed immediately after the two new question as Questions 9 and 11.

- An additional elimination. i.e. ‘no response’ was added to Question 11.
- Responses to Question 13 were revised to sound more moderate.
- In Question 15, ‘All of the above’ was changed to ‘all of the below’ for those who wanted every possible option.
- Questions 17 and 18 were merged to only ask Question 18 if the answer to Question 17 was yes.

6.6.4. Summary

This activity was primarily expected to be *protective* in ensuring the questions in the questionnaire made sense and had the potential to meet its aims. Since the participants responded to the questions as part of the pilot, it was also *inquisitive* and *informative*. The responses *directed* the revisions by rephrasing and changing of several questions which was also *expressive*.

This activity did not identify any new *purpose*, *beneficiaries* or *artefact features*. Instead it provided an *evaluation* of the Questionnaire, an *evaluation* resource.

6.7. Activity 11 - Fielding of the Survey and Analysing Findings

Following the changes made to the questionnaire as explained in Activity 10, participants were recruited to complete them. This section presents an overview of the participants, the approach used, and the findings.

6.7.1. Surveying Professionals

This section discusses the findings of the questionnaire, which was delivered to professionals, identifying any new information where relevant, or confirming assumptions made based on earlier studies. This further strengthened the design arenas *artefacts*, *beneficiaries* and purpose via an *evaluation*.

6.7.1.1. Participants

Ten professionals from educational and health care backgrounds completed the questionnaire.

6.7.1.2. Method

Participants were recruited from or through personal contacts. All of them were involved in professional capacity e.g. GP, SLT, teaching assistant with varying experience with disabled individuals. Three participants completed paper versions of the questionnaire and the others completed the online version.

The response to each question was analysed with reference to the purposes and needs identified in the design process. ‘Traffic lights’ were used to indicate confidence in the design of the artefact using red, amber and green (see Appendix C6 – Questionnaire Findings Professionals). Confirmation of the assumptions and missing information were also identified.

6.7.1.3. Findings

A summary of the findings are provided in this section, the details of which are in Appendix C6-Questionnaire Findings Professionals.

1 – Age of person cared for: The overall age of individuals with special needs ranged from new-born to over 100. Assessment centres could be focused around a specific purpose, e.g. educational needs, and GPs normally do not have special age groups. This posed a challenge for inclusiveness in the design solution (some participants confirmed assumption and others expanded age range).

2 - Number of, and relationships between care circle members:

2.1: The number of members of care circles ranged between 1 and 15. This was an interesting discovery as the professionals believe they are already part of a large care circle (confirmed assumption).

2.2 and 2.3: New roles that have not been thought of, or assumed, e.g. speech pathologist, physical therapist, were identified, and the number of care circle members listed exceeded what had been assumed (added to missing information).

This was positive as the assumed size of care circles was confirmed and it helped improve understanding of the complexity of care circles.

From the design perspective, pre-defined roles could be included in the artefact to select when creating the care circle member's profile though the initial list may be biased as the participants were an opportunity sample, which showed implications for design. If a role was not listed the user should be able to define their own job description.

3 – Internet features currently used: The responses confirmed that all participants had access to, and regularly used, a computer and the Internet, which confirmed an assumption (confirmed assumption and provided information for F).

4 – Current methods of communication: Some respondents did not mark the likert scale for 'some communication media'. Other likert responses 'media such as homework book', did not apply to professionals who are not involved in education settings. However, all professional respondents regularly used different types of online and offline communication methods to keep in touch with other care circle members about the individual concerned. However most of the methods used were one-to-one or one-to-few communications, which other care circle members would probably be unaware of (some participants confirmed assumptions and provided additional information on D but some did not fully respond to this question).

These responses confirmed the need for artefact features such as emails, chats, forums and discussion.

5 – Preferred method of communication: None of the participants selected 'unlikely' or 'very unlikely' for looking for online solutions to questions they may have, and a majority opted for 'very likely', suggesting that all professionals would potentially look online for information (confirmed assumptions and provided missing information on what methods of communication are used, and which are preferred, and when).

6 – Importance of peer support: The response to whether they would benefit from networking with peers was 100% positive and confirmed that it was important for members of the care circle to support each other (confirmed assumptions).

7 – Quality of current communication: Most professionals appeared to be happy with the existing solutions. This could be due to them being the ones who choose the

medium of communication, and making the maximum use of the existing communication options. This could also be due to each ‘patient’ they care for being one of many (responses were spread from confirmation to contradiction of assumptions and missing information on what is good about the current situation and what is not ideal).

8 and 9 – Characteristics of current communication: When rating effective communication and the positive qualities they would like to retain, except for one disagreement over ‘flexibility of alternatives’, the professionals seemed to predominantly agree on the positive qualities of the current methods of communication being timeliness, helpfulness, regularity and empathetic. There were a few who selected the ‘neutral’ response to Question 9 or did not respond at all. This showed that this was a situation that could be improved. An effective design solution should improve the current situation to accommodate more options and therefore, these qualities were integrated into Worth Sketch Version 3 (responses were spread from confirmation to contradiction of assumptions, adding missing information for Question 8 and confirmed assumptions in Question 9).

10 and 11 – Qualities of current communication: The responses provided some useful points for what should be avoided as regards user experience in the design of the artefact.

Even though Questions 7 and 8 appear to give a positive view of the current situation, responses from Question 10 clearly showed that participants also had negative associations with current communication systems, as shown by responses of family members such as ‘reluctance’, ‘ambiguous’, ‘abrupt’, ‘patronising’ and ‘apprehensive’. This emphasised the need to improve the current situation and points to negative user experiences that the features of the potential *artefact* should seek to avoid and therefore, these qualities were integrated into Worth Sketch Version 3 (confirmed assumptions and provided missing information).

12 – Internet usage frequency: Overall this was an encouraging response as all professionals appeared to check their emails at least once a day.

However, the scale may have been flawed with ‘much’ placed below ‘several’. This was not picked up in the pilot test. It was not possible to say if the participants looked at where they were visually placed or marked according to what it read. Therefore both of them were given the same weighting in the interpretation (confirmed assumptions and provided missing information on demographics).

13 – Preference for off the record communication: Most professionals believed off the record conversations are useful or very important. Design options should consider text, voice or video chat options where records are not held. This was a new addition to the requirements (confirmed assumption and provided missing information).

14 – Potential topics and features for social network: The topics of information professionals that wished to discuss with legal guardians were, in order of preference, education, entertainment, assistive technology, therapy, assessment, care and hygiene. This will be taken into account when deciding which features or information should be facilitated in the interface (confirmed assumptions and provided missing information on desired information on site).

15 - Potential topics and features for social network: Most users requested that all features listed in the previous questions to be included. However, most of them also included additional suggestions for features such as file storage and information on support for carers, psychological needs and funding.

The suggestions show that some of the features (e.g. file storage) requested are normally not included in social networks but instead mainly used in e-learning environments. This makes the concept of a social network too narrow. However, as it is to be a custom built system, the file storage/repository can be included in the features. The artefact would also need to be called something other than a social network. The information related requests could be added to the other information sections (confirmed assumptions and provided missing information).

16 – Concerns about social networks: Except for one, all participants had concerns about social networks, most of which included relating to privacy and security, which provided additional information on concerns of potential users. It was important that this challenge was met by designing a system that is secure and providing the

participants with an assurance that this is the case (some participants confirmed assumptions and provided missing information, others showed concern).

17 and 18 – Future participation: Most participants agreed to participate in future studies (confirmed assumptions and provided missing information).

6.7.1.4. Questionnaire Summary

The professionals' version of the questionnaire had 19 questions (including sub-questions) including two questions designed to find out if participants would be willing to participate in future studies. The questions were designed to test 15 assumptions and find six sets of missing information from Tables 6.6-6.7. The responses to 14 questions confirmed assumptions or produced incomplete or missing information. The responses to five questions partially confirmed assumptions, while none of the responses completely contradicted the assumptions. Partial contradictions are marked in amber in Appendix C6 – Questionnaire findings professionals. Eg. the age of cared for is correct but needs to be broader; not all participants are happy with all tools at their disposal.

6.7.2. Surveying Family Members

6.7.2.1. Participants

Five members from five different families completed the questionnaire. One of the forms was completed by both parents. All participants were personal contacts. Further recruitment was attempted via professional networks but was not successful.

6.7.2.2. Method

Three participants completed hard copies and the two completed the online version. The response to each question is analysed with reference to the purposes and needs identified in the design process. 'Traffic lights' were used to indicate the direction in the design of the artefact using red, amber and green (Please see Appendix C6 – Questionnaire Findings Family Members). Confirmation of the assumptions and missing information were also identified.

6.7.2.3. Findings

1 – Age of person cared for: The age range of the children or adults reported by the families reduced the range from 0-100+ (mentioned by the professionals) to 40 and below and provided missing information.

2 – Number of, and relationships between care circle members:

2.1: Family members thought care circles had fewer members (less than 10) than the professionals (up to 15). If the design solution could show the care circles with job titles or roles without revealing name or other details, for example the Speech and Language Therapist, legal guardians of other care circles may be encouraged to invite their child's Speech and Language Therapist to join the care circle (the responses confirmed the size of the care circle but also provided additional information on perceived numbers).

2.2: Two members of the same care circle completed forms and it was interesting to note that although the one member of the care circle (sister) considered herself involved in the decision making, the view of the second family member, (the mother) was that 'only' she and her husband made decisions.

In another case, it was interesting to note that a single form was completed by both parents. It may be useful to consider a single account named 'parents' if they do not want to have separate accounts (the responses confirmed most already identified information and added missing information).

It is also interesting to note that although the professionals include family members as part of the care circle, the family members have not included any professionals as part of the care circle. This is an interesting design challenge to see if family involvement and their perception of the care circle's size could be improved. The membership numbers and perception can be evaluated through a developed artefact.

2.3: The researcher was personally acquainted with all family members who completed the forms and the responses and background were already known to be siblings and parents (the responses confirmed assumptions). This largely influenced

the participant sample and clarified the perspective of the responses in willingness to offer details and also future participation.

3 – Internet features currently used: All of them used email, however none of them used blogs or video messaging. With only two of them using social networks, there may be a need for some persuasion needed to get them to use one. Interestingly, some parents who did not use social networks seem to use features such as chats and updates that would be part of a social network. This might simply be a matter of calling a social network something else that might make the artefact more appealing (some of the participants confirmed assumptions and others did not).

4 – Current method of communication: Some responses were blank and other answers were influenced by the fact that they all cared for someone in primary or secondary education. The responses also showed that all family members regularly used different types of online and offline communication methods to keep in touch about the individual concerned. However most of the methods used were only used for communications between a few members of the care circle, which the other care circle members would probably be unaware of. It was also interesting to note that there is more reliance on the homework book that was the shared communication tool (missing information) between family members and the school compared to the professionals (the responses confirmed most already identified information and added missing information).

In the design solution, it will be important to be able to select the entire care circle or select or deselect specific members of the care circle to share content. The user should also be able to add further members during the discussion later on. For members of the care circle who would only use offline methods, it should be possible to add them as offline participants, but print off a copy to send by post. This option should be given only to the official carer as this could involve protected personal information (i.e. their postal address).

5 – Preferred method of communication: Except for one participant, family members appeared to be comfortable searching for information online. Through postal communication with the reluctant participant, it became clear that she needed more confidence in using the Internet and if she was provided with a direct URL via email,

she would be happy to look for information within the site. This could be a matter of reassurance but was an interesting challenge. The technical consideration of being able to share a URL as a resource or via email could also be considered, this is not an insurmountable barrier. While providing IT training to care circle members may not be within the scope of this research, resources for carers could be made available (the findings covered the full range of answers and did not confirm assumption of all participants accessing the internet for information).

6 – Importance of peer support: The response to whether participants thought peer networking important was 100% positive and confirmed that it is important for members of the care circle to support each other (the responses confirmed most already identified information and added missing information on the importance of peer support).

7 – Quality of current communication: Next to the response to Question 6, the response to how well the current communication was, looked less positive yet if this was considered independently, this would be a positive response.

Most family members appear to be happy with the existing solutions (missing information on what is good). Family members were more concerned about information itself rather than the communication method. The only negative response could be due to the carer feeling that the professional is treating her child as one of many ‘patients’ (missing information on what is not ideal); however, the proposed design solution should improve the current solution (the responses confirmed most already identified information and added missing information).

8 and 9 – Qualities that should not change or need improving: Except for one negative response for quality of current communication on ‘empathy’, two neutral responses and one without a response, the family members seem to predominantly agree on the positive qualities. There is room for improving the current situation. An effective design solution should ideally improve the current situation to produce more positive responses (the responses confirmed most already identified information and added missing information on what is good about the current situation).

10 and 11 - Qualities that should not change and need improving: The responses provided some useful points for what to avoid in terms of users' experience. Even though Questions 7 and 8 appeared to give a comparatively positive view of the current situation, responses from question 10 clearly showed that participants also agree with several negative qualities of current communication systems in place, as can be seen from family members' responses such as 'reluctance', 'ambiguous', 'abrupt' and 'patronising'. This emphasised the need for improving the current situation and confirms qualities of experience that should be avoided in the features for the potential artefact (the responses confirmed most already identified information and added missing information on what is not ideal about the current situation).

12 – Special needs of care circle members: The 3 points mentioned about why care circle members may not be able to participate in online activities were all about the same family member and from two care circle members of the same child. The mother had problems with her English (as her second) language, difficulty using IT skills and is also elderly (missing information). Good usability and accessibility could potentially reduce these challenges and if the social network is successful, the facility to opt to use other languages could perhaps be considered (the responses were confirmed by some of the participants and not others, but all provided missing information).

13 – Internet usage frequency: Overall this was an encouraging response as all family members appear to check their emails at least once a day (the responses confirmed most already identified information and added missing information).

However, the scale may have been flawed and open to interpretation with 'much' placed below 'several'. It is not possible to say if the participants looked at where they were visually placed or marked according to what it read.

14 – Off the record conversation: All family members agreed that off-the-record conversations to be useful or very important. This was consistent with the responses from the professional members of the care circle. This meant the design process should consider text, voice or video chat options where records are not held (the responses confirmed most already identified information and added missing information on preferred method of communication).

15 – Potential topics and features of social network: The responses clearly list the information in demand in order of priority: Education, Therapy, Assessments, Care and Hygiene, Entertainment and Assistive technology. This will be taken into account when adding content to the information base (the responses confirmed most already identified information and added missing information on opinion on social networks).

16 – Potential topics and features of social network: Similar to the professionals' questionnaire, the features/information that the family members would like to use were listed in order of priority. Some of the features requested such as document repository are mainly used in e-learning environments. This may mean using an e-learning platform to develop the artefact and naming it appropriately. The information and artefact priorities of family members do not match those of professionals. If possible, the information provided should be different or customisable to the family members (the responses confirmed most already identified information and added missing information on opinion on social networks).

17 – Concerns about social network: The responses as expected, as privacy and security concerns will exist and social environments are more likely to be vulnerable; the responses are similar to professionals' responses in most cases, as all family members had concerns. It is important that this user experience challenge is met by providing the participants with an assurance that the platform would be secure (the responses confirmed most already identified information and added missing information on opinion on social networks).

18 – Future participation: Most family members agreed to participate in future studies but some declined (this partially confirmed assumptions and provided information).

6.7.2.4. Questionnaire Summary

The family members' version of the questionnaire had 20 questions (including sub-questions). The questions were designed to confirm 15 assumptions and find 6 sets of missing information recorded in the worth tables. Two questions were to find out if they would be willing to participate in this study again.

The responses to 15 questions confirmed assumptions and produced missing information. These are marked in green in the detailed record of responses in

Appendix C6 – Questionnaire Findings Family. The responses to five questions partially confirmed assumptions; these are marked in amber. No responses completely contradicted the assumptions.

6.7.3. Summary

Activity 11 was *inquisitive* as it elicited findings in relation to care circles about *beneficiaries, purpose* and *artefacts* that were *informative, protective* and *expressive*.

The assumptions and missing information in Section 6.4 (Tables 6.6 and 6.7) were confirmed by the responses to the questions as follows (Table 6.9-6.10).

Table 6.9 -Key

Incomplete and Missing information
A. What is good about the current situation
B. List of what is not ideal about the current information
C. List of what could be better about the current information
D. What methods of communication are used, and which are preferred, and when
E. Opinion on Social networking
F. Demographics, including IT access, of care circle

Table 6.10- Responses that Confirmed Assumptions

Assumptions confirmed	Associated Missing Information	Associated question
1. The situation is not ideal because:	A, B, C	
a. Time and distance limitations prevent all members of care circle from participating in all meetings;		6, 10, 11, 12
b. Only dedicated professionals can answer queries even when peers/other care circle members might know the answer, but need to wait. But, this is a major time and financial investment from professionals;		6, 10, 11, 12
c. Assessment is usually only once a year;		4
d. Child may be unable to communicate problems between professionals and family members;		4, 10, 11
e. Multiple methods of communication are independently accessed, unstructured and uncoordinated;		4, 7, 8, 10
		7, 8, 10

Assumptions confirmed	Associated Missing Information	Associated question
f. Children are treated as one of many 'patients' or isolated g. It is impossible to provide technical support on AT devices; h. Therapy and help is offered onsite (location) only; i. Need to search various website and databases to find relevant information on schools and opportunities and still not have reliable answers; j. Information pack is obtained only in hard copy;		4, 10 4 4, 5 4
2. There is a need for frequent communication within care circles	D	4, 5, 13 (professionals only), 14
3. The care circle members own a computer and access the internet	F	3, 4, 5, 12 (professionals only), 13
4. That social networking is a viable solution	A, E, F	3, 4, 5, 6, 8, 9, 10, 12 (professionals only), 13, 14, 15, 16, 17, 18
5. Care circle membership is between 2-7	F	2.1, 2.2
6. Age of Cared for is 0-16	F	1

All assumptions were shown to be correct, but assumptions 5 and 6 were extended to include any age and up to 15 care circle members. Some concerns were identified and in addition, new information was identified from the responses.

The following summary provides a list of findings for each design arenas:

- *Beneficiaries:*
 - B19: The artefact should be inclusive of all ages;
 - B20: The total number of members of a care circle could be as many as 15;
 - B21: Additional roles suggested by respondents included psychomotrician nurse, care trust, education interventionalist, healthcare assistant, nutritionist, orthopaedist, and neurologist;
 - B22: All participants have access to internet and a computer;
- *Evaluation:*

- E5: Fifteen assumptions either partially or fully confirmed;
- *Artefacts:*
 - A38: The artefact should include both predefined roles and allow for new roles to be added;
 - A39: Joint accounts should also be permissible (e.g. Parents);
 - A40: The artefact should also include a feature for a resource repository. This may have to result in a platform that combines both a social network and an e-learning environment;
 - A41: It should be secure and have good privacy settings;
 - A42: It should include a homework book or enable the printing of homework type information;
 - A43: Care circle members should be able to select or deselect who receives group messages;
 - A44: The artefact should include the option to have both on- and off-the-record conversations, via text, audio and video chats;
 - A45: Parents may not always assume professionals to be part of the care circle and therefore prompting them to consider professionals for membership consideration may be beneficial.
- *Purpose:*
 - P11: The artefact should provide support that is timely, helpful, regular and empathetic;
 - P12: It should reduce reluctance, ambiguity, patronising behaviour and apprehension;
 - P13: The artefact should reduce singling out individuals by not intruding or making them feel like they are one of many and cause loss of identity;
 - P14: The artefact should provide reliable information; this is more important than the methods used to provide it.

6.8. Worth Sketch Version 3

Analysis of the questionnaire data (Appendix C6 – Questionnaire Findings Family and Professionals) shows that all of the assumptions were partially or fully confirmed and missing information was identified. A further Worth Sketch (Version 3, Figure

6.3) was produced to reflect the analysis of the questionnaire data. The changes to the Worth Sketch are as follows:

- Both worthwhile outcomes and adverse outcomes increased by one item each;
- New worthwhile outcome j was added; ‘shared specific information is independently accessible’;
- Worthwhile outcomes b and c had comparatives ‘more rapid’ and ‘more appropriate’ added to indicate improvements;
- Worthwhile outcome g had characteristic ‘flexibility’ added;
- Both items i and j were replaced with ‘reliable and important documents ready to hand’;
- All adverse outcomes were re-written to correspond to worthwhile outcomes;
- There were no changes to any other design arenas at this stage.

Worthwhile Outcome	a. More frequent engagement of more care circle members	b. More rapid improvements individual personal social and environmental factors	c. More appropriate and timely support by more members of care circle	d.g. Improved communication	e. Better informed life style support	f. Don't feel isolated	g. Better, flexible AT support	h. More frequent and accurate assessments	j. Reliable information ready to hand	j. Important documents and forms ready to hand	k. Shared specific information is independently accessible
Worthwhile Experience	a. Manageable schedule	b.e. Dependable knowledgebase	c. Satisfactory Service	d. Confident communication	e. Reduced stress	f. Motivated	g. Moral Support	h. Reduce time and travel demands	i. Empathetic environment	j. Convenient	
Qualities	a. Flexibility of time and distance	b.c.g.i. Effective & efficient	d. Accurate & reliable	e.g.i. Informative & helpful.	f.g. Caring, encouraging, motivating	h. More frequent help	j. Technically accessible				
Features	a. Live & Synchronous participation	b. Platform where any care circle member could respond	c. Frequent and continuous assessment	d. Professionals and fairly regular communication.	e.i. Support services	f. Know who is the individual's care circle	g. AT support from developer and peers	h. Video and/or self-help therapy	j. Available for download		
Materials	a.g. Chat, discussion boards	b.g. Wall posts, forums	c.h. Online assessment forms, videos	d. Alerts, personal messages, status update	e.g.i. Resource sharing	f. Visual overview of care circle members	h. Video chat	j. Multiple formats			
Adverse Experience	a. Fewer decision Makers	b. Support and advice delay	c. Assessments only annual	d. Poor professionals-family communication	e. Too many methods of communication	f. Feel isolated	g. Insufficient tech support	h. Poor off-site support	i. Inconsistent, unreliable or no information	j. Inflexible solutions	
Adverse Outcomes	a. Few care circle members frequently participate	b. Lack of impromptu tips and tricks from peers for individual's lifestyle	c. Lack of support by members of care circle	d.g. Breakdown in communication between school and parents as individual struggles to communicate	e. Waste time repeating information and miss out on receiving possible useful information	f. Feel singled out and 'just another child' (instead of unique and special)	g. Little, and even no, technical support for AT devices	h. Assessments are bi annually or annually; children grow fast	j. Difficult to identify reliable sources and readily available information	j. Only hard copies available from specific sources by special permission	

- a. Time and distance limitations prevent all members of care circle from participating in all meetings;
- b. Only dedicated professionals can answer queries even when peers. Other care circle members might know the answer but need to wait. But, this is a major time and financial investment from professionals;
- c. Assessment is usually only once a year;
- d. Child may be unable to communicate problems between professionals and family members;
- e. Multiple methods of communication are independently accessed, unstructured and uncoordinated;
- f. Children are treated as one of many 'patients' or in isolation;
- g. It is impossible for assessment centres to provide technical support on AT devices;
- h. Therapy and help is offered onsite (location) only;
- i. Need to search various websites and databases to find relevant information on schools and opportunities and still not have reliable answers;
- j. Information pack is obtained only in hard copy.

Figure 6.3- Worth Sketch Version 3

Worth Sketch Version 3 was next used to refine the technical requirement specifications for development (Chapter 7).

6.9. Summary of Iteration 3

The aims of this iteration were to corroborate findings from Iteration 1 and Iteration 2 prior to finalising the initial design of the *artefact*.

Chapter 6 opened with Worth Shift Tables and Artefact Component Tables. Worth Sketch 2 then extended the range of explicit connections between design arenas. Worth Integration Tables were considered but are no longer needed to connect the design arenas but instead, the Worth Sketch (Version 2) was directly updated.

The next step was the use of a novel design method to design a questionnaire that focused on both intended worth and the *artefact*. Each question had a rationale based on, or a specific focus on, sources identified in the tables that recorded assumptions to be confirmed and missing information to be identified. The questionnaire was piloted, and each question was empirically revised and documented.

The questionnaire was then fielded and the data analysed. As the data referred to the specific stakeholders in this study and not to the general public, the participant numbers for completing the questionnaire were sufficient at this stage. However it was insufficient to be validated statistically and the data was used qualitatively. The data obtained from the questionnaire strengthened the understanding of *beneficiaries* by separating them into professional and personal roles.

The results helped to establish if the beneficiaries had the expected needs, desires and difficulties, and whether the proposed form of solution would be welcome. This information was then used to produce a further Worth Sketch (Version 3), through the identification of further Worth Sketch components, as well as revisions to existing value, experience and feature elements. Important qualities were identified which were incorporated into the existing Worth Sketches between the feature and experience elements.

Worth focused questionnaire design (Activity 9) was an original resource contribution to knowledge. It is original in being designed using Artefact Connection Tables and

coordinating with the Worth Sketches. It is also original in how the questions were planned, related to identified assumption and incomplete or missing information.

6.10. Reflection on Iteration 3

This iteration of RtD focused on the process for designing a novel worth focused questionnaire that integrated findings from Activities 1-8, identified knowledge gaps and evaluated them. This was also balanced of focus (worth) in considering all design arenas and via worth shift tables; integration of foci via worth sketches and assumptions and incomplete or missing information tables and focused on purpose for every question. This involved using findings from previous Activities (1-8) and this entire iteration also consisted of primary activities. This process was predominantly sequential but Activity 6, the discussion with a care circle member, took place after the process had started, which contributed to the broadening of age range.

6.10.1. Order of Activities 9-11

The initial response to the findings listed in Chapters 4 and 5 was to move straight on to creating a questionnaire that would obtain the information needed to develop a suitable system. However, this approach was abandoned and a more challenging and rigorous approach was taken where, based on findings from Activities 1-8, Worth Shift Tables and Artefact Connection Tables were created, and from these tables both missing information and assumptions were listed and then the questionnaire was designed. The entire process including the analyses of data took approximately eighteen months (part-time) to complete between June 2009 and December 2010. Activity 6 (discussion with family member of care circle) took place in October 2009 and was used to go through the questionnaire and was also used to pilot the questionnaire.

Table 6.11 - Order of Activities

Chapter 6: Activities 9-11	
<i>June 2009</i>	Activity 9: Questionnaire Design Started
<i>January 2010</i>	Abandoned initial approach and started with Current-Ideal table; assumptions and missing info: systematic progress to questionnaire design
<i>April 2010</i>	Numbered assumptions; missing info; prioritised current-ideal; Pre-Pilot checks
<i>May 2010</i>	Activity 10: Pilot started
<i>June 2010</i>	Pilot completed
<i>July 2010</i>	Revised for Fielding
<i>August 2010</i>	Activity 11: Fielding
<i>September 2010</i>	Fielding completed
<i>November 2010</i>	Questionnaire Data Analysis started
<i>December 2010</i>	Traffic lights introduced
<i>January 2011</i>	Worth Sketch I (Appendix)
<i>March 2011</i>	Worth Sketch II

While the questionnaire was anticipated to be a single activity, this turned out to be more work than predicted, and involved three activities (design, pilot and field) and several Worth Expressions (Worth Sketches, Artefact Connection Tables, Worth Shift Tables).

6.10.2. Scope of Iteration 3

The questionnaire design (Activity 9) and piloting (Activity 10) were fundamentally focused on the *artefact*. However, the questions themselves were focused on both the *beneficiaries* and the *artefact* (Figure 6.4). The pilot showed an evaluation of the connections between artefact and beneficiaries and artefact and purpose. It was also an evaluation of the evaluation.

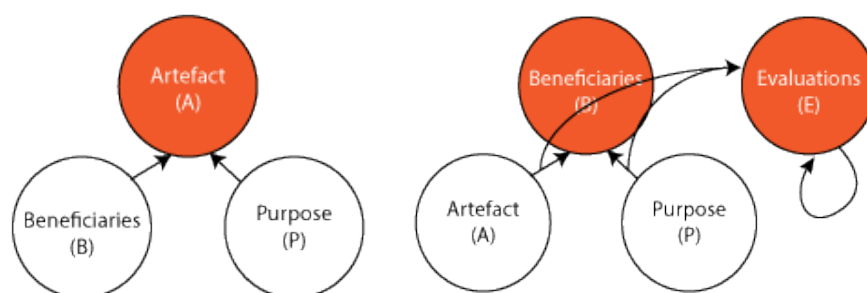


Figure 6.4- Most Abstract Design Situation (MADS) for Questionnaire Design and Pilot

The fielding of the questionnaire and the findings were *evaluation* focused (Figure 6.5). It evaluated the connections between the design arenas and also evaluated the fielding process. Thus, Chapter 6 has several foci of co-ordinations. At this point in the process, the findings were reflected on in preparation for the initial design stage.

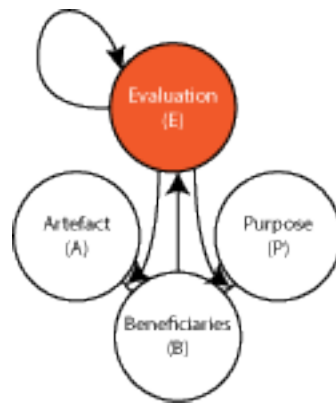


Figure 6.5 - Most Abstract Design Situation (MADS) for Questionnaire Fielding

As with Activities 1-8, the anticipated findings from Activities 9-11 did not match the actual findings. The questionnaire design, piloting and fielding anticipated balanced foci on beneficiaries, artefacts and purpose in the evaluation of proposed features and checking assumptions. However, questionnaire design started with artefact and beneficiary foci and coordinated beneficiary, artefact and purpose. The focus shifted back to beneficiaries but more connections, including to/from evaluation, were added to the coordination of the remaining design arenas during the piloting. During the fielding and evaluation, the focus shifted to evaluation and the other three design arenas were iterated. The overall primary generator for this iteration was evaluation (Figure 6.6).

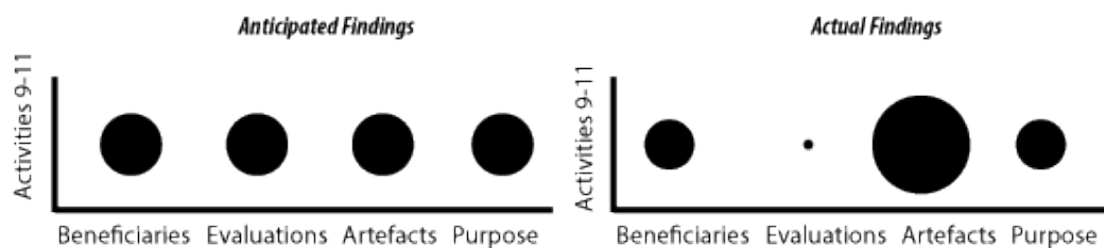


Figure 6.6 – Proportional Abstract Design Situation (PADS) of Activities 9-11 - Questionnaires

6.10.3. Progress in Iteration 3

Iterations 1 and 2 provided information on *beneficiaries*, *artefacts* and *purpose* for the proposed design solution. The purpose of Iteration 3 was to organise this information, identify any gaps, confirm the information and fill any gaps.

Activities 9 (Questionnaire Design) and 10 (Questionnaire Pilot) did not contribute to *beneficiaries*, *artefact* or *purpose*. They contributed to *evaluations* in the form of designing and piloting the questionnaire. Activity 10 was also an *evaluation* of the *evaluative* tool.

Activity 11 was an *evaluation* in itself but contributed significantly to *purpose*, *beneficiaries* and *artefact* and shifted the design arenas as shown in Table 6.12.

The conclusions from this iteration are as follows:

- A social support system, based on values recognised by care circle members, is suited to meet the needs identified in the previous iteration.
- All assumptions made from previous activities are correct.
- The artefact features identified in the Artefact Connection table were confirmed.
- The emphasis for the system should be based on the increased benefits and reduced costs and risks identified and confirmed through this survey.
- While the membership of care circle needs to be controlled, it is not exhaustive.
- An age limit is not necessary for the disabled individual.
- As recognised in Chapters 4 and 5, this Iteration (3) also acknowledged that general solutions are unsuitable for individuals with disabilities and emphasised the need for an easily adaptable, platform.
- Some concerns eg. security, were identified and in addition, new information was identified from the responses.

The following Table 6.11 shows the shift of each design arena in this iteration.

Table 6.12 – Iteration Shift for Chapter 6

	<i>From</i>	<i>To</i>
<i>Beneficiaries</i>	Improved understanding of family and professional roles and confirmed their response to a potential social tool.	Involvement of both professional and family care circle members.
<i>Evaluation</i>	Explored potential for existing social network and building from an existing framework.	Confirming assumptions, identifying incomplete and missing information by professional and family care circle members.
<i>Artefacts</i>	Integrated communication within a social support and information system.	Confirming assumptions, identifying incomplete and missing information on requirements for the social support and information system.
<i>Purpose</i>	More holistic understanding of worth for care circles. Being sensitive to values of beneficiaries.	Confirming worth-centred user benefits from the artefact.

6.10.4. Resource Functions Analysis

As shown in Table 6.13. the questionnaire was *expressive* and both the pilot and fielding were *inquisitive*. The findings were directly *informative* for the design and were *invigorative* where the researcher had to analyse the findings further prior to applying to design directly. The confirmation of assumptions was *protective* and strengthened the existing findings. The questionnaire as a resource provided a space for those who completed it to be *expressive*. Questionnaire data extended the perceived membership of care circle roles to include additional roles, thereby being *informative*.

Table 6.13 – Realities of Resource Functions in Iteration 3

Activity	Resource	Achieved Functions
Activity 9	Questionnaire Design	Expressive, Directive, Protective
Activity 10	Questionnaire Pilot	Expressive, Informative, Inquisitive Protective, Directive
Activity 11	Questionnaire Fielding and Analysis	Expressive, Informative, Inquisitive, Protective
Cumulative Functions		Informative, Expressive

Collectively, the designing, piloting and fielding provided findings that were mostly *informative and expressive*.

6.11. Next Iteration

This chapter focused on confirming the requirements for a probable *artefact*. The Worth Integration Tables recorded the findings from all activities and expressed a Worth Shift that was identified by reducing costs, lacks and increasing benefits. Worth Sketches also recorded the addition of new information for moving the current to an ideal situation for stakeholders. Further, the questionnaire design itself had a continuous focus on improving the current situation. The questionnaire responses confirmed assumptions and identified missing information. Worth Integration Tables and Worth Sketches expressed the worth of potential design artefact. The findings will be carried over to the next chapter where the detailed design of an initial artefact begins.

Iteration 4 will not require a shift in the understanding of *beneficiaries* or *purpose*. Artefact is expected to shift to become more specific. The focus of the next iteration is to create personas, design and develop the artefact. Creation of Personas (Activity 12) was anticipated to be an integrative activity that focused on beneficiaries and purpose but also highlighted how artefact features would be connected to. Activities 13-15 were expected to focus entirely on designing and developing the artefact.

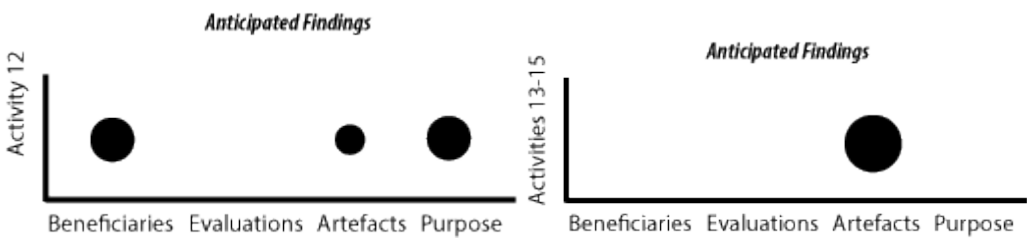


Figure 6.7 - Anticipated Proportional Abstract Design (PADS) Situation for Iteration 4

The anticipated shift in design arenas is shown in Table 6.14.

Table 6.14 – Anticipated Iteration Shift for Chapter 7

	<i>From</i>	<i>To</i>
<i>Beneficiaries</i>	Involvement of both professional and family care circle members.	Not expected to change
<i>Evaluation</i>	Confirming assumptions, identifying incomplete and missing information by professional and family care circle members.	Not expected to happen.
<i>Artefacts</i>	Confirming assumptions, identifying incomplete and missing information on requirements for the social support and information system.	Specifying detailed requirements for the social networking system.
<i>Purpose</i>	Confirming worth-centred user benefits from the artefact.	Not expected to change

Chapter 7 - Iteration 4: Design and Development of Chosen Artefact Version I

Design of the questionnaire, the pilot study, the fielding of the questionnaire, the results, and the confirmation of assumptions and the discovery of missing information identified in Chapters 4 and 5 were reported in Chapter 6. The findings from the analysis of questionnaire fielding needed to be organised in a form that could be used for the design of the artefact.

This chapter records in detail how information was organised and used to create personas that in turn provided detailed user journey and clear requirements for the design and development of the social support system. The development of this system was then outsourced and built to requirement. Personas, Requirements Specifications and Screen Wireframes recorded in this were given to the developer, who submitted them as requirements from client for his own research project with SAE Institute.

7.1. Activity 12 - Personas

A Persona is a specific, but imaginary, user who is part of the target user group. Personas are used to help imagine a real user trying to accomplish the goals within an interactive interface. Cooper (1999) invented and popularised the notion of personas, and Pruitt and Adlin (2006) provided personas with a more rigorous lifecycle. The five phases of their lifecycle are: family planning; conception and gestation; birth and maturation; adulthood and lifetime achievement and retirement. Pruitt and Adlin (2006), describe in detail, with various examples, how the entire cycle could be followed to build realistic and successful personas. Pruitt and Adlin (2010, p.2) say “building personas from assumptions is good; but building personas from data is much, much better”. The findings obtained and confirmed in Chapter 6 was used as a basis for creating personas for the artefact. Context and purpose of tasks were identified over Chapters 4-11. The personas were narratives used to integrate them, then writing tasks for requirements for each type of user, and later evaluating the developed artefact.

7.1.1. Method

While the concept of personas was taken from Pruitt and Adlin (2010), the Persona Toolkit developed by Olsen (2004) was used as a framework to structure personas. Olsen's Toolkit supports defining the persona type for prioritisation and uses sixteen categories to define each persona as follows.

- Biographic background
- Geographic profile – refers to where the participant is from
- Demographic profile – refers to age, gender, family structure, employment, social class and education
- Psychographics – refers to status, network role, personality and self-image, beliefs, attitudes, receptiveness to innovation, motivations, traits, hobbies and media usage habits
- Webographics – refers to type of internet package they subscribe to and amount of online usage, device usage and specific online behaviour
- Personas relationship to business
- Product's business relationship to the persona
- Specific goals, needs and attitudes
- Specific knowledge and proficiency
- Context of usage
- Interaction characteristics of usage
- Information characteristics of usage
- Sensory/immersive characteristics of use
- Emotional characteristics of usage
- Accessibility issues
- Design issues

Based on the information elicited so far, and what the personas were going to be used for, Olsen's structure was simplified from sixteen categories to five categories as follows:

- Geographic profile
- Demographic profile

- Psychographics
- Webographics
- Relationship to proposed product, goals and needs

The categories relating to business were dropped, as this research does not have a business context. Other usage and competency related information were included in a new section ‘Relationship to proposed product, goals and needs’.

Biographic information on the users was limited and was also not necessary to be able to design and therefore the section on Biographic background was also dropped.

These personas were primarily *integrative*, and *expressive* of existing findings and also *protective* in checking coordination between design arenas. This new persona structure was also *directive* in recoverable autobiographical memory, revisiting activities, and enabled addressing any oversights. The information required for these categories within the structure were obtained from the detailed records of Activities 1-8 in Appendix C4 and C5 and, where they were not available, creative assumptions were made by the designer based on informal conversations with the participants of this research and personal experience.

7.1.2. Design Process

As part of the second phase of the personas lifecycle (Adlin and Pruitt, 2010), persona conception and gestation, the range of personas together with the required details were identified. The identified personas were also prioritised as follows.

Focal personas are the primary users of the system. The design needs to be optimized for them. At least one persona must be a focal persona with up to a maximum of three (Olsen, 2004) to ensure the system to be designed is appropriately focused.

The list of care circle members was based on questionnaire responses 2.2. The numbers at the end of each type of care circle member indicate the number of times they have been mentioned in the questionnaire responses as whom the participants considered members of their care circle. Care circle members mentioned the most number of times were turned into personas from responses to Question 2.3. The

number of times each member is mentioned in the questionnaire responses is in brackets.

1. Family Caretaker including Parents (10), Grandparents (7), siblings (2), other relatives/cousins (3)
2. Speech and Language Therapist/ Speech Pathologist (8)
3. Teacher/Special Education Teacher (8)
4. Occupational Therapist (8) or Physical Therapist (3)
5. Physician/GP/Paediatrician (7)

Parents received the highest count and mother was chosen as a persona. Speech Therapist was chosen as the second personas they received the second largest count. The GP was chosen as the next highest count is for medical practitioners.

Secondary personas also use the system. The design will meet their needs whenever possible.

1. Psicomotrician (4)
2. Social Worker/Health visitor (4)
3. Nurse -Practice/District/Hospital (4)
4. Carer (3)
5. Psychologist (3)

Unimportant are low-priority users, including infrequent, unauthorised or unskilled users, as well as those who would misuse the system.

1. Educational Interventionist (1)
2. Physical Education Teacher (1)
3. Doctor (neurologist, orthopaedist) (1)
4. Nutritionist (1)
5. Technologist (1)
6. Health Care Assistant (1)

Affected users do not use the system themselves, but could be affected by it.

1. Child and Adolescent Mental Health Services/Primary Care Trust/Autistic Advisory Service (3)
2. Practice Manager (1)
3. Learning Disabilities Team (1)
4. Director of Assessment (1)
5. Swallowing evaluation specialist (1)
6. Project manager (1)

Exclusionary users are those for whom the artefact is not designed for. It is often useful to specify this to prevent non-users from returning to considerations. In this research, the design solution was not aimed at the disabled child at the centre of the care circle. While the proposed artefact concerns the disabled individual, this individual was not expected to be a user of the site. The care circle membership is to be created and managed by the carer or legal guardian.

While the persona development had not started until this iteration, in retrospect, it can be understood that data gathered over the course of Activities 1-11, shaped the personas, fulfilling phase 3: persona birth and maturation. Three personas from the list of primary personas were chosen and developed as shown in 7.1.2.1-7.1.2.3. The findings from previous activities (that informed the questionnaire questions) and informed or personal creative additions are continuously stated against each statement in red text. Some of the narrative information provided in this section may not be included in the DAP lists in Chapters 4 and 5 as they would have been too descriptive and were not significant as contributions.

7.1.2.1. Persona 1 - Susan



Figure 7.1 - Persona 1 (Source: CC 1.0 Public Domain)

Susan: Focal Persona

Geographic profile: Susan lives in London with her husband and three daughters [Activity 1 - Preliminary contextual inquiry revealed most children had 'able' siblings and both parents].

Demographic profile: Her daughters are aged five years, three years and one year respectively. [Question 1, age of the individuals the majority of participants cared for] and Susan is in her mid-thirties [Children from Activities 2 and 3 were five years old, the age when AT is decided and children are moved to mainstream schools]. Susan holds an English Degree and was a secondary school teacher by profession but gave up teaching and became a full-time carer soon after her oldest daughter Nina was diagnosed with Cerebral Palsy when three months old [Activity 3, most parents had good careers and some mothers had given up theirs to care for their 'special' children].

Susan had seen other individuals with cerebral palsy but had never been knowledgeable or taken any special interest in this condition until Nina's diagnosis [Activity 4 - Some parents had never heard of the condition and/or details of CP, while others had but without the details]. In addition to dealing with the trauma of discovering Nina's condition she needs to know how to provide Nina with the best possible opportunities possible to have a good quality of life. [Activities 3 and 4 - Parents need more information and would like to communicate with other, more experienced parents]. Susan would like to know how other parents in similar situations support their children and also needs information from reliable sources on education, communication support, feeding, therapy and assistive technology [Activities 3 and 4 – Parents need more information and would like to communicate with other, more experienced parents]. As special needs assistance is expensive, she would also like information on financial support and fundraising [Questions 15 and 16 list the features that the majority of carers would like to have in the proposed artefact and any concerns they may have].

Susan and her husband's parents, some of their family friends, and Nina's godparents are also very interested in Nina's development [Activity 4 - Close extended family at heart of care circle].

They constantly phone and visit to check on her and the rest of the family [Question 12 - frequency of access and Question 2.2, membership of care circle].

Susan and her husband come from middle-class families and Susan's husband is the breadwinner. As both Susan and her husband are British they also get support from the British government to care for Nina [Activity 3 and 7 - All families were middle class EU citizens with access to the NHS].

Psychographics: Susan regularly keeps in touch with Nina's schoolteacher, occupational therapist and speech and language therapist [Activities 2-3 - At least one parent kept regularly in touch with the professionals involved]. This is usually by phone, email or notes that are written in Nina's homework book [Question 3 – preferred methods of communication]. As Nina also cares for the other two children, the school transport picks up and drops Nina from home so Susan does not get to see much of the other parents or children [Activities 2-3 - The usual situation when the child has siblings, Question 2.2 – most common number of perceived care circle members]. She constantly wonders if there was more she could do to improve Nina's lifestyle and where and how she could find this information [Activity 4 - Parents are unsure if they should do anything more]. She is receptive to any new technology or support that could possibly improve Nina's communication [Activities 2-3 - Preliminary contextual inquiry showed most parents were willing to try new AT to improve lifestyle of child].

Susan understands Nina's method of communication better than anyone else and wishes more people would understand Nina [Activities 2 and 3 - All parents seem to understand their children's communication more than any other care circle member; Question 5; Activity 4 - Those in regular contact understand child's unique way of communication]. She relies on the advice of the school and disability assessors to educate herself and help Nina.

When Nina returns from school, Susan regularly checks her homework book for notes from anyone in school [Activity 6 - method of communication the care circle members rely on]. She frequently emails and phones Nina's support team, that consists of approximately seven people to ask for advice on feeding, communication and activities, at times wonders how the other parents do it [Question 2.1 – average number of methods of communication used is 3].

She does make a mental note to contact some of them but rarely gets around to doing it. If they organise or tell her about any fundraising events, she is sure to take part [Activities 1 and 7 - information care circle members would like to have].

Susan and her husband have a family car and also a smaller car for errands [Personal experience, a practical example - special seating for CP children may require more space]. They spend as much time as possible together as a family. They go to the park on weekends and whenever else they can weather permitting.

Webographics: They also play Wii games and watch movies at home [Question 3 - to communicate tech savvyness]. They have access to the Internet and a computer at home [Question 3 to communicate tech savvyness]. Susan is an active Facebook member and checks her email and Facebook at least twice a day [Question 12 – average frequency of Internet access]. Susan is aware of the possible security issues on Facebook but at times this is the only way to keep in touch with others [Question 17 – is interested in other options].

Relationship to proposed product/goals/needs: Susan keeps in touch with some mothers of children from Nina's school [Question 6 – most parents believe it is important to communicate with other parents]. As a result of her contact with both her support team and other mothers, she ends up repetitively sharing the same information, which is time consuming [Derived from discussion during questionnaire pilot]. She also has to explain to her extended family members how to communicate with Nina [Activity 2, some children had booklets explaining how to communicate and for other children the support worker had to explain.]. Susan would like a single platform where Nina's support team, her extended family members and other parents could contribute and support Nina [relevance of this personas to the design solution].

7.1.2.2. Persona 2 - Rachel



Figure 7.2 - Persona 2 (Source: [CC by 2.0](#) Steven Depolo)

Rachel: Focal Persona

Geographic profile: Rachel lives just outside London and travels to work about 30 minutes by car to a primary school and has her private clinic at home where she sees patients in the evening and on Saturdays [Informed creative addition based on Activity 7].

Demographic profile: She has been a Speech and Language Therapist (SLT) for almost 20 years and is now in her mid-forties [Based on findings of Activities 1 and 7]. She started her career when most of the assistive technology was low-tech (non-computer-based) but has gradually adopted many of the computer-based solutions [Based on findings of Activities 1 and 7].

Psychographics: She works with children from the time they are diagnosed with the need for speech therapy and also with some adults who have suffered strokes and need rehabilitation [Question 1 – average cases of children SLTs work with]. Rachel has worked in this field for 20 years and has dealt with complex cases so is very knowledgeable in her practice. She also trains other speech therapists new to the job. She works in a primary school and also has a private practice at home [Based on findings of Activities 1 and 7].

Despite Rachel preferring low-tech devices over web-based or high tech devices, if it makes her job easier or efficient, she is willing to spend time figuring out new technology [Question 16 – concerns regarding new/social networking systems]. However, she would like to have reliable tech support from the manufacturers and also from other users [Question 15 – desired features of new system].

She does make an effort to join her own children in playing computer games and browses the web for any new updates on assistive technology [personal creative addition based on findings of Activity 2-3].

Webographics: Her secretary can only take note of queries from her clients and Rachel would need to wait until she gets time until she can respond. Most of the time she needs to talk to the contact (legal guardian) again for clarity [Informed creative addition]. She finds this time consuming [Question 15 – desired features]. She usually has to check the patient’s file and also any electronic correspondences before responding [Question 3 – current methods of communication]. In addition she may have to look at visuals (images or videos) in order to be more helpful [Question 15 – desired features]. She would like to see all the information in a single place and also know when the next scheduled meeting is so that she could plan accordingly [Question 15 – desired features of new systems; 16 – concerns of new system].

She takes times to learn new software, but she is comfortable with emails and using the internet [Informed creative addition based on participant of Activity 2-3]. In addition to the regular time she spends with her patients, she also responds to email enquiries [Informed creative addition]. If any of her patients or their guardians phone to ask questions, most of the time she is unable to answer the phone as she is with other patients [Question 3 – current methods of communication and 7 – and how good it is]. There are times when she thinks that the parents could help each other sooner than she can get back to them [Question 6 – desire to be in touch with other parents]. She also thinks that some of the parents could find information online rather than waiting for her response [Question 15 – desired features]. Whenever she finds useful information, she would also like to have a repository to allow her to share it with her patients [Question 15 – desired features of new systems; 16 – concerns of new system].

Relationship to proposed product/goals/needs: Rachel has always been reliable but would like to provide support in a timelier manner [Personal creative addition]. She does not want to stop using off-line methods of communicating such as letter and phone but would like to offer more online options as it is easier to manage, and information can be shared more easily online [Questions 8, 9 –desired qualities and order of priority for new system]. She likes to provide accurate and detailed information, but not too much to avoid confusing her clients [Question 10 – priority for improving communication and Question 11 – family members who have technical difficulty].

7.1.2.3. Persona 3 – John

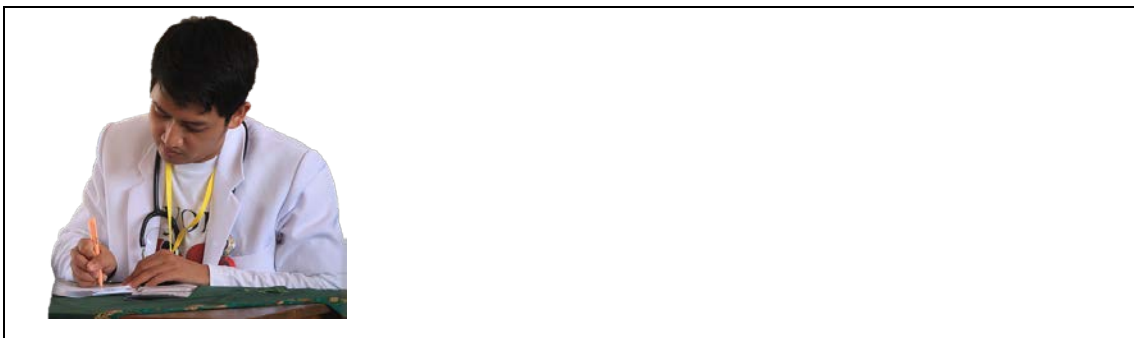


Figure 7.3 - Persona (Source: CC0 1.0 Public Domain)

John: Secondary Persona

Geographic profile: John works as a hospital based GP in NHS, Birmingham.

Demographic Profile: John is in his 40s and works three days a week at a local clinic and two days a week at the local hospital as a GP [Informed creative addition based on Activity 7].

Psychographics: He works with patients of all ages [Question 1 – average age of individual cared for]. Sometimes when patients try to explain children with special needs' progress in relation to development milestones, he has to phone or write to their therapists and school to get more accurate data [Question 3 – current methods of communication and 4 – preference]. By the time he gets the information the child could have improved further, or problems could have got more complex.

He sometimes wishes he could get a glimpse of all the notes of progress made by the support workers involved with these children to speed things up and be able to help his patients in a timelier manner [Questions 8 and 9 –desired qualities and order of priority for new system; 14 – topics of discussion with care circle members and 15 desired capabilities of website].

He periodically attends training programmes and workshops for medical practitioners to stay up to date and also keeps in touch with his colleagues [Question 6 – desire to be in touch with other parents].

Webographics: He uses the NHS database to add and edit patient records each time he sees a patient. He has an NHS email [plausible addition]. He is an active Facebook user, but he uses this only when he is not working [plausible addition]. He also regularly reads online about current research and medical updates. He also plays computer games with his children during weekends [Question 3 – current methods of communication and 4 - preference].

Relationship to proposed product/goals/needs: John is comfortable balancing his two jobs but would like to be able to easily access all his information in a central organised location [Questions 8 and 9 –desired qualities and order of priority for new system]. He also believes this way he could spend more time with each patient and can ensure that he is not abrupt. He is very efficient and also expects his patients to act responsibly [Questions 10 – priority for improving communication, 11 - and for family members with technical skill challenges].

7.1.3. Summary

Activity 12 consolidated existing findings and was primarily *expressive*. As it was *expressive* of *beneficiaries*, *artefact* and *purpose* they are *worth-focused personas*. Personas will *inform* and *direct* the development of the social support system. These personas will also be used as a reference to evaluate the system as part of cognitive walkthrough recorded in Activity 16 in Chapter 8. Activity 12 was not expected to and did not modify existing design arenas but mapped the *beneficiaries'* identification of purposes and artefact features to representative beneficiaries.

7.2. Activity 13 - Requirement Specifications

The personas, that were created using findings from previous activities were used to produce developer resources. The three chosen personas covered *purposes* identified over the activities recorded through Activities 1-11. In addition, they also activated some previously undocumented insights and options that were recorded as informed or personal creative additions. As the personas have now been developed, they were used to specify the requirements and used for development, which is ‘Persona Adulthood’, that is phase 4 of its lifecycle (Pruitt & Adlin 2006).

The aim of this activity is to produce specifications for the development of the *artefact*.

7.2.1. Method

The first element in this activity is the expression of the usage context as a task list, intended to help the developer of the artefact understand when and how the artefact would be used. This is followed by a description of the aims of the website and its features. Additional information on the system intended to assist the developer is also set out.

As there was a hesitancy recognised in the usage of the term ‘social network’ and the features required extended the usual concept of a social network, the social support system website was named *My Care Circle*.

7.2.2. Developer Resources

This section focuses on how a potential user would use the website and provides information on the anticipated performance of the user and records the scenarios, aims, features and other project information that were provided to the developer together with information on the source of the findings.

7.2.2.1. Usage scenarios

The following are scenarios built based on a carer’s journey in caring for a disabled individual and are to help understand the context in which the artefact would be used.

These scenarios are based on the most common practice derived from the activities relating to interviews, observations and reflection and the proposed usage of the artefact.

- When a child is first diagnosed with a motor impairment such as Cerebral Palsy, the medical practitioner or social worker recommends that the mother registers on the website. The mother looks up the information section and finds documents with information and support on 'Cerebral Palsy'.
- The mother invites the medical practitioner, social worker, special educational needs teacher and speech and language therapist to join the child's network on the website.
- The entire team populates the social space with information about education, communication, feeding, financial support, fundraising, therapy, etc.
- The mother videos the child communicating and eating using her mobile phone and shares the video using the website with the speech and language therapist and the teacher. The therapist proposes a few assistive devices; the family members and other care circle members consider the options and choose collaboratively.
- The mother regularly posts progress updates including photos, videos and notes to inform those involved in education and medical support of progress so that they could make further suggestions.
- The mother invites other parents from the school of the child to join the care circle, if she thinks they could be part of the care circle.
- When the therapists are unavailable, the mother posts any concerns or questions on the website in the form of text, photos or videos so that when they do become available, they can see the entire content and respond after checking any records which are also available on the website. Alternatively, other parents can respond from their experience;
- The care circle can also gradually build a shared document or profile on the artefact on how the child communicates, which will become useful for any new

teacher or therapist when they take over. This reduces duplication of information and makes training easier;

- Having connected with a number of people on the care circle, if the mother has any security concerns, she looks at the information on security and is able to manage the access or consult the system administrator;
- The mother can choose to get email alerts about relevant news or other useful information; she could also choose to share any interesting information she finds with others, and if others share information with her, she can set up the system to alert her.

7.2.2.2. Aims of the *artefact*

The overall aim of My Care Circle is to bring together professionals and family members who care for individuals with motor impairment to form care circles, to allow them to network with other professionals and parents, discuss and debate issues online and thereby improve the care of the individual with the impairment. It is also the aim of My Care Circle to be a repository for reliable resources relating to all aspects of caring for a disabled individual. Based on findings from the previous iteration, this will be a cross between a social network and an e-learning environment. The purpose of the website is to support the care circle members as follows:

- Share information about the progress of disabled individuals;
- Enable remote assessments of disabled individuals to be conducted;
- Provide a means by which therapy can be conducted remotely and to allow therapy related information to be passed on remotely;
- Improve choice of, and support in, using assistive technology;
- Enable more supported education by providing information on suitable schools and other learning opportunities for children;
- Support and train both professional and family carers to care for disabled individuals;
- Provide details of suitable entertainment for disabled individuals;
- Provide information and guidance on care and hygiene of disabled individuals;

- Support the psychological needs of those with disabilities and members of their care circle;
- Provide details of funding opportunities.

Based on responses to **Questions 8 and 9 of the questionnaire**, the website needed to provide the following user experience qualities:

- Timely – a care circle where anyone can help and the carer does not need to wait for professionals to respond;
- Helpful – both private and public posts and question and answer options will enable more individuals to respond and find answers;
- Flexible – a platform where several methods of communication and disability assessments are possible;
- Regular (frequency of review) – carers do not need to wait for periodic review for communications;
- Empathetic – care circle members who are experienced in responding to similar situations can respond;
- Informative – provides diverse materials that can be used for free and gives quick access to information that is not in books or articles.

Based on responses to **Questions 10 and 11**, the website should seek to reduce the following user experience defects:

- Reluctance – by creating a user friendly environment;
- Ambiguity – by including both on-the-record methods such as message and posts that provide generic responses and off-the-record communication methods such as video chats that can provide confidential but specific information;
- Abruptness – by providing, or having links to further explanation/information to complement professional advice
- Patronising content – by allowing users to choose what information they wish to view;

- Feeling of apprehension amongst users – by giving clear cues to indicate confirmations and responses to activities on the website by email on the website;

Based on responses to **Question 17**, the following risks should be taken into consideration:

- Privacy and Security – secure log in and data protection;
- Timeliness and reliability of response – swift responses from those who are authorized and invited to;
- Time demands for participation and use – tasks should be simple, easy, and take the minimum time possible.

7.2.2.3. Requirements: Creating and managing care circles

Potential screen designs were sketched to capture the functionality from the perspective of the legal guardian, the wireframes of the interface included access, view and permissions as shown in the Design Activity 14 in Figure 7.2 for My Care Circle.

The legal guardian of the individual concerned should create the profile of the individual they look after. Thereafter, they should add members, select the relationship status of new members and send an invitation to those they think are involved in the support and care of the child or adult they care for (i.e. care circle member). The care circle member should click on the link, accept and register. This gives the legal guardian control over membership.

The member (the added individual) should be able to confirm or change their relationship to the individual concerned. For example, if the guardian added him or her as teacher when in fact a teaching assistant, this change should be possible and if this does not exist, the user should be able to define their own relationship. The guardian should also be able to select an ‘other’ option and define new roles. The following options could be given in a drop down.

Based on responses to **Questions 2.2 and 2.3**, the following roles should be in the drop down menu for the user of the website:

Professionals

Speech and Language Therapist	Health Care Assistant
Speech Pathologist	Physical Therapist
Teacher	Psychologist
Special Education Teacher	Child and Adolescent Mental
Occupational Therapist	Health Services
Physician coordinates	Primary Care Trust
GP (General Practitioner)	Autistic Advisory Service
Paediatrician	Educational Interventionist
Psycomotrician	Physical Education Teacher
Social Worker	Neurologist
Health visitor	Orthopaedist
Nurse: Practise / District /	Nutritionist
Hospital	Technologist
Carer	

Family member

Mother	Uncle
Father	Relative
Brother	Family friend
Sister	Step mother
Parents	Step father
Grandmother	Step brother
Grandfather	Step sister
Grandparents	Step grandfather
Aunt	Step grandmother

Based on responses to **Question 6**, where potential users wish to communicate with peers (parents to parents or teachers to teachers), once registered, the member should be able to see the profiles of other care circle members.

Following registration, users should be able to login using email and password, which is a process used by many social networks and should therefore be familiar to most users.

7.2.2.4. Features: Provision of capabilities, access and sharing

Based on the responses to **Question 17** that indicated concerns over privacy and security, the legal carer should have control over what features should be viewed or used by each care circle member, as this could involve protected personal information (i.e. postal address).

The following features should be available for the care circle member to use. Based on responses to **Question 15**:

- Forums or discussions;
- Feedback on queries about the disabled individuals;
- Progress updates for/on the child;
- Text, voice or video chat options where records are not held;
- Follow up online assessments;
- Calendar;
- File storage and access to helpful information (e.g. downloadable files);
- Ability to view previous records.

Based on responses to **Question 14** related to sharing information online, it is important for a user to be able to select either the entire care circle or specific members of the care circle to share content with. Users authorised by the legal guardian should also be able to add further members during ongoing discussions.

Based on the responses to **Question 4** relating to preference of communication methods, an authorised care circle member should be able to add members of the care circle who would only use offline methods such as homework books or printouts of communication as ‘offline’ participants and print off what they need.

7.2.2.5. Content categories

There should be some default categories of information for all users as seen below, based on the responses to **Questions 14 and 15** where the types of information that potential users may seek were identified. However, the contents of these categories will be populated and shared by care circle members:

- Assessments
- Assistive technology
- Care and Hygiene
- Education
- Entertainment
- Funding assistance

- Psychological Needs
- Support for carers
- Therapy
- Technical support for assistive technologies

There should be a ‘share’ option for any discussion of posts in these categories, which could send a URL via email.

7.2.2.6. Usability

Based on responses to **Question 12** good usability and accessibility could potentially reduce many of the challenges faced by the care circle members. If the social network is successful, other languages than English could also be considered.

7.2.2.7. Accessibility

Based on responses to **Question 12** the site must comply with W3C WAI (World Wide Web Consortium Web Accessibility Initiative) level AAA Guidelines.

7.2.2.8. Code validation, search engine optimisation, hosting and support

In line with standard industry practice at the time of outsourcing this development, all code on the site was required to conform to W3C (World Wide Web Consortium) specifications.

However, as a beta version, no search engine optimisation was required and an appropriate host site will be provided and administered by the researcher in line with the ethical approval.

The contract was signed for Version 1 to end by August 2011 and Version 2 by November 2011. In addition to fixing and reported bugs, the site will be on maintenance mode for the remainder of the study.

7.2.3. Summary

Activity 13 *integrated* existing findings and was primarily *expressive* and *informative* to the developer. This *informed* and *directed* the development of the *artefact*. It also provided the developer with guiding principles and user context (see Appendix C7 –

RequirementSpecs). This was used as part of the contract between the researcher and the developer. This activity did not unearth any new design options, but focused on communicating the artefact requirements.

7.3. Activity 14 - Design

Once the technical requirements had been written, visual preferences were identified and provided to the developer of the system.

7.3.1. Method

In order to brain storm for look and feel for the site My Care Circle, the following questions were shared on Facebook Group private message with randomly selected participants to gain some insight into what type of visuals users expect to see in a social network that offers care. The questions were:

1. What is the colour of care?
2. What is the shape of care?
3. What are the first visuals that come to mind when you think of care?
4. Any creative or crazy ideas that you would use to describe care.

In addition, the architecture of site content was sketched into wireframes by an interface designer colleague from Goldsmiths, University of London as I talked him through the usage scenarios.

7.3.2. Findings

17 participants responded to the questions as follows in Table 7.1:

Table 7.1 - Visual Ideas

Participant	Colour of care	Shape of care	First visuals	Other ideas
P01	pale blue	pillow shaped	U like a comfortable hammock	
P02	pink	circle	mother	
P03	blue	round	red cross	
P04	light blue	medical cross	hands, arms, holding/enveloping	
P05	blue	round	helping	hands and hearts
P06	blue	heart	Old peoples' homes, mental help facilities	hugs and holding hands
P07	pink (fusion) & cyan	circle	hands	"to love is to care"
P08	red	heart	vulnerable people	Smile, hugs, tears
P09	sky blue	round	holding hands, young and old hugging and smiling/adult and child holding hands and walking	cats or dogs licking people or their peeps' wound
P10	light green	circle	cuddle	cuddle; love, support, respect, smile cry
P11	pink	circle	hand; faces	hand; faces
P12	warm blue moving towards pink	round/elliptical	hug	hand stroking, smile, sun break through cloud
P13	pink	heart	big hand holding small hand	big hand holding small hand
P14	blue or yellow	circle	big hand reaching out to small hand	Heart

Both the shape and colour reflected the associations people had with the term 'care'. Blue was marginally the greater preference to pink with blue receiving 6.5 votes and pink receiving 7. Both the designer colleague and the researcher cast the deciding vote and chose pink as the theme colour. It was also decided that the shapes used for the design should not have any sharp edges. When further icons or visuals were needed, these findings would also serve as a resource. The logo, for example, was designed using multiples circles for Version 2 of the website (see Chapter 9).

Potential screen designs from the perspective of the legal guardian were sketched as part of a collaborative design exercise to capture the functionality (Figure 7.4) by an interface design at Goldsmith, University of London, as the researcher talked him through the usage of My Care Circle.

Two wireframes of the interface were needed to included access, view and permissions of the users (Figure 7.4).

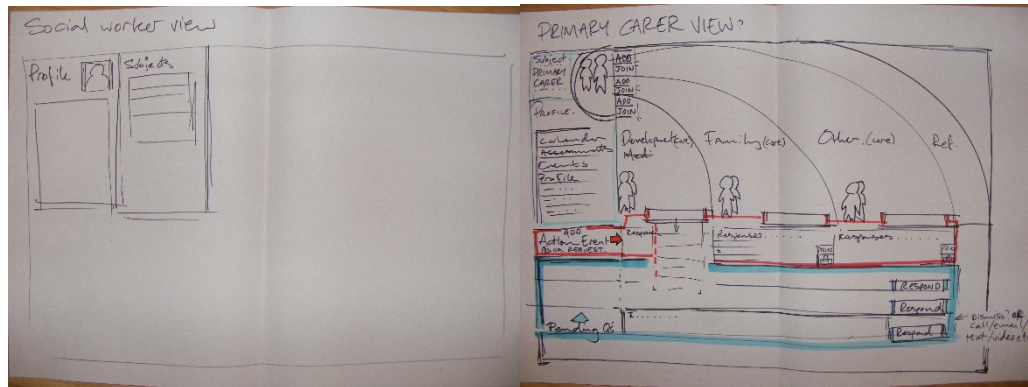


Figure 7.4 - Wireframe from Carer and Social Worker View

Card sorting activities were carried out to structure the content and tasks as shown in Figure 7.5.

The personas were referred to ensure the purposes and associated features were considered during the design process.



Figure 7.5 - Card Sort for Content Design

7.3.3. Summary

Activity 14 was primarily *expressive* and was intended to be *informative and directive* to the developer. This will *inform, direct* and potentially *invigorate* the development of the artefact. This was used as part of the information provided to the developer. This activity was *protective* for the design process as it provided a design before development. As expected, this activity did not extend any design arenas. However, it continued to be a reinforcement of the existing artefact design and demonstrated progressive instantiation.

7.4. Activity 15 - Build

Based on the requirement specifications and the wireframes, the first version of My Care Circle was built.

7.4.1. Method

The scripting languages used were HTML5, CSS3, PHP, MySQL, FLEX, Flash, JavaScript and jQuery. The development framework used was Code Igniter. As discussed in Activity 8, CAT model, the emphasis the development of this custom built social support system was to make it accessible.

7.4.2. Findings

Design and development took approximately nine months for the researcher and developer. During this process, it also became evident that the developer had poor UX and design judgement and may have benefitted from more detailed design instructions. Screen shots of Version 1 of the site and its various pages can be found in Chapter 8 as part of the evaluation.

Due to the emphasis on accessibility, dynamic content such as continuously refreshing sections or pages had to be avoided. This resulted in AJAX, which is a widely used scripting language for social networks, not being used. Version 1 of the website was functional and quite basic in design but was ready for initial evaluations to be carried out.

7.4.3. Summary

Activity 15 *integrated* existing findings and was primarily an *integrative* and *expressive* activity carried out by developer. It resulted in Version 1 of the artefact envisaged as the outcome of the design process. This activity did not unearth any new design arenas.

The website was evaluated using extended Cognitive Walkthrough, Expert Heuristic Evaluation and User Walkthrough. The results are reported in Chapter 8.

7.5. Summary of Iteration 4

The aim of this iteration was to use the findings from the previous iteration and develop an *artefact*. The aim of Activity 12 was to create personas that represented the three major user groups. The aim of Activities 13 and 14 were to document both technical and visual requirements that were necessary for the development. The aim of Activity 15 was to build the artefact. All aims were achieved.

As seen in Activity 8 of Chapter 5, none of the existing social networks reviewed are fully accessible, but the specifications required this site to be accessible which, was the biggest challenge. Activity 15 revealed that the combination of social network and information repository similar to an e-learning system was more technically demanding than expected.

The final outcome of this iteration was Version 1 of the website, My Care Circle (MCC).

7.6. Reflection on Iteration 4

This iteration of the Research through Design process largely consisted of design and development where the process was focused on the *artefact* and wholly sequential.

7.6.1. Order of Activities 12-15

The requirement specifications in Activity 13 were written in December 2010. The design Activity 14 was conducted in January 2011 over a day with an additional day of reflection. This was followed by the second design activity that identified colours and visuals in February 2011 when the personas were also written and given to the developer along with other visual requirements. Version 1 of the site development was completed in November 2011. Activity 15 did not include any milestones for reviewing progress and providing feedback. However during the 9 months that it took for the developer to complete Version 1 of My Care Circle (MCC), feedback was provided on design and functionality at two update points (Table 7.2).

Table 7.2 - Order of Activities

Chapter 7: Activities 12-15	
<i>December 2010</i>	Activity 14: Requirement spec;
<i>January 2011</i>	Activity 13: Co-Design; Activity 12: Persona with commentary;
<i>February 2011</i>	Activity 13: Colour of Care; Activity 15: Start Development
<i>August 2011</i>	Activity 15: Feedback to Developer
<i>October 2011</i>	Activity 15: Feedback to Developer
<i>November 2011</i>	Activity 15: Version 1 of site Complete

7.6.2. Scope of Iteration 4

The purpose of activities in Chapter 7 was to create a set of personas and to plan and design the artefact. This naturally makes the focus on the artefact as shown in Figure 7.6, but as they were refining activities for the artefact, the connection was artefact *to* artefact. This was used to develop the first version of MCC. This design leads to the next stage, recorded in Chapter 8.

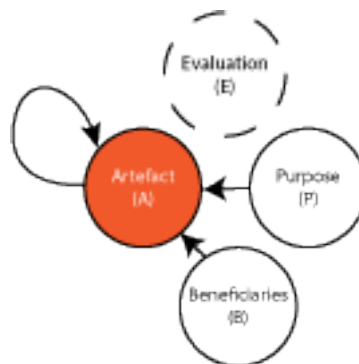


Figure 7.6 - Most Abstract Design Situation (MADS) of Chapter 7

The anticipated focus of the design arenas over Activities 12, 13 and 14 corresponded to the actual findings (Figure 7.4-7.6). These activities were not expected to increase understanding or refinement of design arenas and instead were coordinating activities. Therefore the PADS presented do not correlate to a DAP list but instead is conceptual.

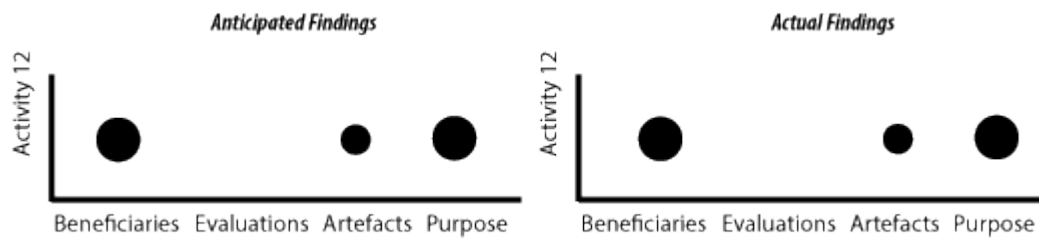


Figure 7.7 - Proportional Abstract Design Situation (PADS) of Activity 12 - Personas

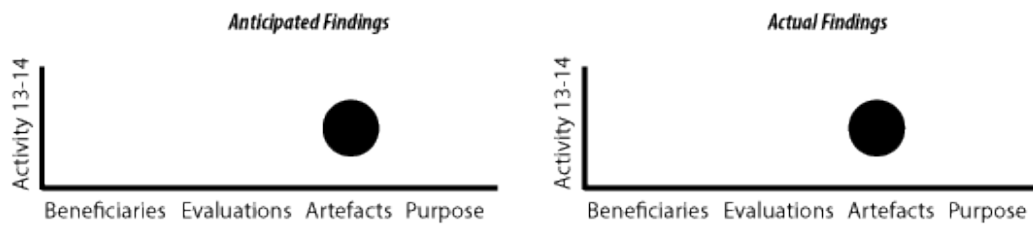


Figure 7.8 - Proportional Abstract Design Situation (PADS) of Activity 13 – Requirement Specifications, Activity 14 - Design

However, Activity 15 (Figure 7.4) had unplanned evaluations, where two sets of feedback were provided to the developer.

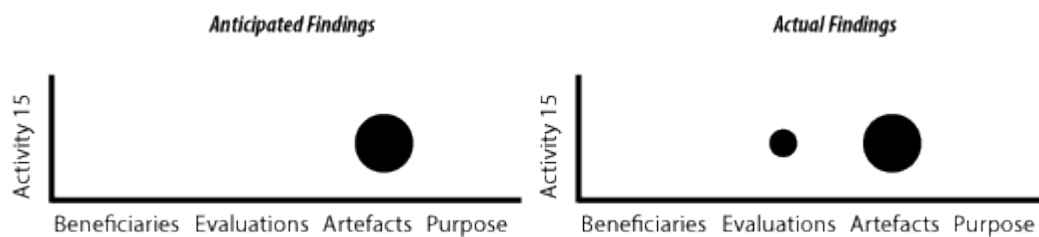


Figure 7.9 – Proportional Abstract Design Situation (PADS) of Activity 15 - Build

Activity 15 provided an artefact that was intended to meet the technical and visual requirements that were specified in Activities 12-14.

7.6.3. Progress in Iteration 4

Activities 12-15 shifted the progress made in Iteration 3 through to design and development.

The continuous presence of beneficiaries during design and development was achieved via the form of personas. The development of the personas also enabled narrowing the users to three primary categories and integrating the beneficiaries, artefact features and purpose that have been identified.

Activity 13 translated the technical information to development requirements for the programmer. Activity 14 interpreted the information to designs and Activity 15, referring to Activities 13 and 14 realised the artefact. This process progressed worth as shown in Table 7.3.

Table 7.3 - Iteration Shift for Chapter 7

	<i>From</i>	<i>To</i>
<i>Beneficiaries</i>	Improving understanding of professional roles	Involvement of both professional and personal beneficiaries were extended by being expressed as Personas.
<i>Evaluations</i>		Functionality testing was done to provide feedback to developer.
<i>Artefacts</i>	Integrating communication, exploring desirability of social networking system;	Finalising requirements for the informative social networking system. Completed first version of MCC development.
<i>Purpose</i>	More holistic understanding of worth for care circles.	No change

7.6.4. Resource Function Analysis

The main aims of Activities 12-15 were to write specifications and develop the artefact.

While the resources used had anticipated functions, they also had unexpected ones. A developer's pack with usage scenarios and technical requirements were provided to the developer. Developer carried out the development based on the requirements provided and his own knowledge and experience in development. However, it was *integrative* of all requirements and *expressive*. The findings from all activities collectively and cumulatively were *expressive* (Table 7.4).

Table 7.4 – Realities of Resource Functions in Iteration 4

<i>Activity</i>	<i>Resource</i>	<i>Achieved Functions</i>
<i>Activity 12</i>	Personas	Expressive, Integrative, Protective
<i>Activity 13</i>	Requirement Specification	Expressive, Protective
<i>Activity 14</i>	Design	Inquisitive, Expressive, Informative
<i>Activity 14</i>	Wireframes	Expressive, Protective
<i>Activity 15</i>	Development	Integrative, Expressive
<i>Cumulative Functions</i>		Expressive

This chapter started with personas in Activity 12 that were *expressive* and *integrative* in its structure. Activity 13 was *expressive* of the technical requirements and *protective* in being as specific as possible for the developer. Activity 14 was *inquisitive* in identifying the visuals and was *informative* and *expressive* in what was identified and provided to the developer. The wireframes in particular were *expressive* and *protective* in providing a visual structure for the developer.

Activities 12-14 were *protective* by designing and working on specifications prior to development and Activities 12-15 were collectively *expressive*.

The next step is to take the artefact to the potential beneficiaries for evaluation.

7.7. Next Iteration

This chapter reported on the design and development of the chosen *artefact* version. It demonstrated how the outline of requirements confirmed in Chapter 6, which were based on by findings from Chapters 4 and 5, were used to create personas and refine the requirement specifications. Based on this, the first version of the artefact, with its capabilities, features and qualities was developed.

This iteration showed a shift in artefact that was realised as Version 1. The focus of the next iteration is to evaluate the built artefact using the Cognitive Walkthrough method, based on personas, expert heuristic evaluation, and user-walkthrough with think-aloud. Following the evaluation, a demonstration and reinforcement study to determine if the need for the artefact still remains will be conducted. Based on the findings, MCC Version 2 was developed.

Activities 16-18 are anticipated to be entirely *evaluative* and Activity 19 is expected

to reinforce the purpose of the design solution.

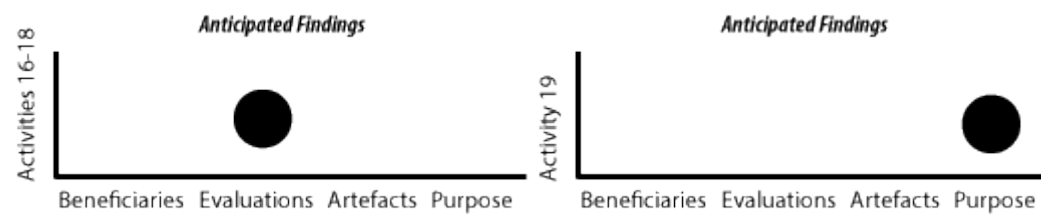


Figure 7.10 - Anticipated Proportional Abstract Design (PADS) Situation for Iteration 5

The anticipated shift in design arenas in Chapter 8 is as shown in Table 7.5.

Table 7.5 - Anticipated Iteration Shift for Chapter 8

	<i>From</i>	<i>To</i>
<i>Beneficiaries</i>	Involvement of both professional and personal Personas.	Continuous Involvement of both professional and personal roles.
<i>Evaluation</i>	Functionality testing was done to provide feedback to developer.	Evaluation of My Care Circle and development of Version 2.
<i>Artefacts</i>	Finalising requirements for the social networking system. Completed first version of development.	Redesign of artefact in response to evaluations.
<i>Purpose</i>	No change (from holistic understanding of care circles)	Purpose extended by potential users.

Chapter 8 – Iteration 5: Evaluation of Artefact Version 1 and Development of Artefact Version 2

Chapter 7 described the design and development of My Care Circle (MCC), which was based on findings from the preceding activities.

The next stage in the project was to evaluate the website. A prototype website is not ready to be tested for use by real participants. However evaluation needed to be triangulated by obtaining feedback from (1) checking against personas (2) web design experts, and (3) potential participants. Therefore, Heuristic Walkthrough (Sears, 1997) which is Cognitive Walkthrough followed by Heuristic Evaluation was chosen. The triangulation was completed with a User Testing. Findings from these activities were given to the developer, who submitted them as evaluation and feedback from client as part of his own research project with SAE Institute.

All evaluations were conducted using the following user tasks. The findings follow the structure of the following tasks and are numbered the same.

Registration, Invites and Log-in

1. Register on MCC
 - a. Registration using full name and email.
 - b. Login afterwards should be by typing email and password.
2. Create care circle:
 - a. Complete own profile and profile of person they care for.
 - b. Select Relationship to the disabled individual from drop down menu
3. Invite new members to MCC
 - a. Existing users
 - b. New users
4. Care circle member
 - a. Accept the invitation
 - b. Register
 - c. Join care circle
5. The 'new' member should be able to see the 'profiles' of other care circle members

6. The care circle creator should be notified and he or she should accept the registration.

Usage

Users should be able to:

1. Start discussions on forums
2. Contribute to discussions on forums
3. Receive feedback on queries in forums or messages about the disabled individual concerned
4. Post or get progress or status updates about the disabled individual
5. Have text, voice or video based chat options which are not recorded
6. Create / follow up online assessments
7. Access the calendar
8. To share files with information on:
 - Assessments
 - Assistive technology
 - Care and Hygiene
 - Education
 - Entertainment
 - Funding assistance
 - Psychological needs
 - Support for carers
 - Therapy
 - Technical support for assistive technologies
9. To view records of child

Selective Access

1. The legal guardian should have control over what features should be viewed or used by each care circle member.
2. Members of the care circle being able to add further members during the discussion later on.
3. The legal guardian should be able to add members of the care circle who would only use offline methods of communication (i.e. printed copies) as offline participants and print off information for them as required.

4. There should be a 'share' option for any discussion or information, which could send a URL via email.

The Selective Access features were not implemented and therefore could not be evaluated.

Since the *artefact* requirements were complex in developing a combination of a social network and e-learning system that was fully accessible, it was also the first time the developer had built anything similar to this. Further, the user experience design was unexpectedly poor. This may be due to the developer's expertise lying in programming rather than the visual design. This was however not fit to be piloted in the real world environment as yet. Therefore evaluations using personas and a limited number of participants were carried out.

Cognitive Walkthrough was carried out by the researcher adopting the personas identified in Chapter 7. This was followed by an expert evaluation using heuristics conducted by the researcher jointly with another colleague, a user interface designer from SAE Institute. Three potential participants also used MCC while thinking aloud about the tasks identified. Finally, a reinforcement study was conducted to assess if the need for this design solution was still valid.

This chapter reports on these activities that were carried out to evaluate the developed artefact.

8.1. Activity 16 - Cognitive Walkthrough

Cognitive walkthrough is a process in which each of the tasks defined for the development of the interface are stepped through and assessed by the researcher (please refer to Chapter 2, Section 2.3.4.2). This activity modifies it as follows.

8.1.1. Participants

The researcher carried out the walkthrough by adopting the personas of Susan, Rachel and John designed in Activity 12 (Chapter 7).

8.1.2. Method

First, the personas were used to help the researcher walk through the following tasks that were based on the usage scenarios that were created as a guide for the developer.

At each step of the tasks, the researcher answered the following four Cognitive Walkthrough questions against each of the personas (Wharton *et al*, 1994), typically all/few at once:

- (1) Will the user try to achieve the right effect?
- (2) Will the user notice that the correct action is available?
- (3) Will the user associate the correct action with the effect to be achieved?
- (4) If the correct action is performed, will the user see that progress is being made toward solution of the task?

The responses from all four personas were recorded collectively.

Based on the findings, the researcher provided feedback to the developer.

8.1.3. Findings

Each group of tasks was evaluated from the perspective of the personas and in the process, user interface recommendations were made, bugs were detected and missing features were noted. The original method has been modified to suit this research by the use of personas, providing a perspective based walkthrough (Zhang, *et al.*, 1998) rather than a cognitive walkthrough. This covered a wider range of user contexts by assessing the potential user experience from the perspective of three primary user groups.

The complete findings together with screenshots are shown in Appendix C8 – Cognitive Walkthrough. The resulting summary of required changes are as per section 8.1.4.

8.1.4. Summary of Required Changes

Activity 16, Cognitive Walkthrough was an *evaluation* identifying findings from the perspective of *beneficiaries* on the usability of *artefact* features. The website design was too poor at this point for the persona based walkthrough to be effective, which resulted mostly in a basic expert walkthrough. While no new artefact features or *purposes* or beneficiaries were added, bugs, implementation oversights were identified and usability problems for the features were identified. Changes to the implemented features were thus necessary. This section uses the structure that was used for the task evaluation to explain required changes.

8.1.4.1. Registration, Invites and Log-in

1. Register on MCC
 - a. Registration should be with full name and email: the options are clear but some detailed instructions are confusing. The confirmation emails should be from the system administrator rather than the developer. The procedure for this task is straightforward.
 - b. Login afterwards should be by email and password to be straightforward and clear.
2. Create care circle:
 - a. Complete profile: generally confusing as to who the profile is for, this should be clear. Instructions are duplicated which results in being confusing. Picture upload is confusing.
 - b. Select Relationship of user to the disabled individual from the drop down menu: clear but picture upload confuses this.
3. Invite new members to MCC
 - a. Existing users: Other than the lock features, everything is clear. For already invited individuals, 'Reject Invitation' should be 'Invitation sent. Uninvite'
 - b. New users: straightforward and clear.
4. Care circle member:
 - a. Accept invitation: feature is functional but the details of the email need to be clearer.

- b. Register: there needs to be a notification to indicate if the invited has signed up instead of having to manually check.
 - c. Join care circle: The steps taken to complete the task can be simplified.
- 5. The 'new' member should be able to see the 'profiles' of other care circle members: This is not possible and as such, they cannot join care circles.
- 6. The care circle creator should be notified and he or she should accept the registration: This is not possible

8.1.4.2. Usage

1. Start discussions on forums: while getting to the section is confusing, starting a discussion is straightforward. The navigation should be clearer.
2. Contribute to discussions on forums: While functional, the feature is confusing. Should have a consistent interface design and navigation.
3. Receive feedback on queries about child concerned: Notifications should be included.
4. Progress or status updates for/on your child: not evaluated
5. Have text, voice or video based chat options where records are not held: The lock is confusing and feature is non-functional.
6. Follow up online assessments: not evaluated
7. Calendar with important dates: non-functional
8. All users should be able to share files with helpful information: clear, except for who it can be viewed by and the lock icon.
9. Should be able to view previous records of child: not evaluated.

8.1.4.3. Selective Access

This feature was not developed and therefore not possible to evaluate.

8.1.5. Summary

Cognitive walkthrough was intended to be conducted purely from the perspective of the personas. However, when suggestions were made to fix the difficulties or bugs, there was a switch to an expert walkthrough.

The cognitive walkthrough as an activity was *inquisitive* and *directive*. It was also *protective* as it was intended to identify problems prior to the system being tested by real users. The findings were *informative*.

- E6: Evaluation
 - 6 registration, 9 usage and 4 selective access tasks were tested by walking the personas through them and whenever the features existed, suggestions for improvements were made.

8.2. Activity 17 – Expert Heuristic Evaluation

Having carried out the cognitive walkthrough, I was aware of challenges in carrying out the user tasks. While individual suggestions can improve them, adopting overall usability principles is likely to improve overall experience. Now that the website has been evaluated from the user perspective using personas to assess how user required tasks could be completed, the second step was to evaluate the website from a web expert view using heuristics (Sears, 1997).

8.2.1. Participants

The researcher and an experienced user experience designer colleague from SAE Institute jointly conducted the evaluation.

8.2.2. Method

The checklist was based on Xerox Corporation's 13 usability heuristics. This is a systems checklist based on Neilson's ten Heuristics and three additional Heuristics (<http://www.stcsig.org/usability/topics/articles/he-checklist.html>, 2011) related to systems. This checklist was chosen as one with most technical coverage and the sections that were not applicable were left out. The detailed check list can be found in Appendix C8 – Heuristic Evaluation. As this perspective of the evaluation is from a web expert perspective, an overview of the website as a whole was also taken in addition to a task based one.

8.2.3. Findings

Several functional and visual problems were identified and recorded against each of the heuristics. For the purpose of this chapter, positive findings have not been included, the complete heuristic evaluation can be found in Appendix C8 – Heuristic Evaluation.

8.2.3.1. Visibility of system status

The system should keep the user informed of what is going on and provide feedback on any actions taken. There are some pages that do not indicate which page the user is on. Some links lead to the incorrect page. Warnings about who would see the information should be made clear and based on where the user is on the website. The usage of the back button and lock icon is unclear. The number of steps for posting questions and answers (e.g. Step 2 of 4) and notification of responses do not exist. Confirmations need to be included when tasks have been completed. A ‘loading’ message while the user waits for response is important, as not knowing what is happening may result in the user not being able to complete some of the tasks.

8.2.3.2. Match between system and the real world

Users should be able to relate to the visuals and language of the site from their real world experience. All visuals except for the lock icon (that is used in a very confusing way to hide and reveal) are familiar.

8.2.3.3. User control and freedom

The user should be able to select the options he or she wants and change his or her mind about it at any point. Naming of menu items should be clearer by making the first word the most important. For most of the features, there is no indication of steps that need to be followed. If a mistake is made, there is no option to edit settings or exit. There is also no undo feature. Prompts should be more brief and unambiguous.

8.2.3.4. Consistency and standards

The text, context and actions should be clear and consistently mean the same thing and also follow usability standards. There is inconsistent use of overtype and insert

text throughout. Icon selection status should be clearer and more consistent. The lock icon is not labelled. Instructions for actions need be more consistent. For example, 'Reject' instead of 'Decline' invitation, 'Upload' instead of 'Share'. Pages should have titles. The notifications and confirmation should always appear in the same place. Font sizes should be more controllable and consistent. The background text colour could also be made more contrasting. There are, confusingly, different messages and formats of the message to invite someone to join a care circle. Error messages should be consistent in format and content.

8.2.3.5. Help users recognise, diagnose, and recover from errors

Error messages should be expressed in simple language without any technical jargon. They need to be made consistent in format and content, which may prevent users from recovering from errors. Some instructions for error recovery are unclear.

8.2.3.6. Error prevention

This heuristic reduces the need for the previous one by reducing errors from occurring. There are no error warnings where too many characters are entered in a field.

8.2.3.7. Recognition rather than recall

Instructions for using the system and its features should be visible at all appropriate times. There are some options, such as the Calendar, that are available only from a certain page. Users should be able to see and access such options from anywhere in the site and not have to remember where to access it from.

8.2.3.8. Flexibility and minimalist design

The site is expected to support expert users by providing shortcuts or accelerated routes to functions and alternative access to those with different needs. This site does not provide customised solutions for different levels of users. All users have access to all features, but this should be customisable by the legal guardian. Accessible colour theme options would be helpful for users with visual impairment.

8.2.3.9. Aesthetic and minimalist design

Information provided via text or visuals should be minimal yet sufficient.

Visual design could be more consistent. The site lacks visual alignment in many places in the design. Different font colours and styles could also be used to indicate error warnings. White space can be used more effectively to guide user between two points and increase legibility of text. Colour coding can be more consistent to help users navigate. Icons should be part of a single family. While the two black icons do not have much detail, the others do. Spacing between images and text could be improved. When the site is accessed from some links, the pages appear broken. The footer should move with the pages, which at times appear disjointed.

8.2.3.10. Help and documentation

While the interface design is expected to be self-explanatory, additional help features should be provided. In its current form, the instructions provided to carry out actions are more confusing than helpful, as the background does not separate them in anyway and information is not easy to find.

8.2.3.11. Skills

This heuristic is an addition to Neilson's ten heuristics, where the interface is expected to support, extend, supplement, or enhance the user's skills, background knowledge, and expertise and not replace them. Some users may navigate the site using visuals, where others would need to read the text that says what it is. When usage increases, users may develop these navigation skills, in this interface, there is no option to switch between text- or image-based navigation. Alternative Tags that explain the images are also missing for the upload image option, which would also increase accessibility. The design of this interface could improve by alternative navigations and text.

8.2.3.12. Pleasurable and respectful interaction with the user

The overall experience with the system is expected to improve the support provided to the disabled individuals. For the experience to be more pleasant, the design could be

improved to be more aesthetically pleasing, with clearer instructions to carry out the functions.

8.2.3.13. Privacy

The system should help the user protect their data and feel comfortable while using the interface. A required feature would be providing complete control to legal guardian for controlling access of each care circle member, which the system does not at present include.

8.2.4. Summary

Activity 17, heuristic evaluation was an *evaluation* of the interface from the perspective of professional web designers, to assess the usability of MCC. While no new *artefact* features or *purposes* or *beneficiaries* were added, bugs and implementation oversights were identified, and usability problems were assessed.

The Xerox checklist that included Nielsen's ten heuristics plus three additional ones was used to assess the usability of MCC. While several features were found to be functional, several areas for improving consistency, aesthetics, simplifying tasks and instructions were identified. Users need to be guided more clearly when following tasks on the website. Navigation needs to be clearer and the aesthetics need to be improved by tidying up the environment and clarifying instructions. Overall the text and visuals need to be made consistent.

This activity was intended to be *protective* by identifying problems prior to testing by real users. The findings were *informative* and *expressive*.

- E7: Evaluation
 - Two experts including the researcher used 13 heuristics to evaluate MCC. Several areas for improvement were recorded and forwarded to the developer.

8.3. Activity 18 – User Testing with Think Aloud

As the third perspective, a sample of potential users needed to provide feedback on the website.

8.3.1. Participants

Three typical members of the care circle participated in the user testing with think aloud.

- Participant 1 was the legal guardian for her sister;
- Participant 2 was a NHS doctor for several disabled children;
- Participant 3 was an Educational Psychologist and swimming coach for children with autism and motor impairment.

8.3.2. Method

Ethical approval to involve participants in the study was obtained from the University. After consent forms were signed by each of the participants, each participant was asked to complete the tasks that were used for Cognitive Walkthrough as much as possible. The researcher was available at hand to intervene if participants got stuck. The findings were recorded in note form and later written up (below).

8.3.3. Findings

Findings from the participants were recorded against each task that was completed. Some of the findings from the Cognitive Walkthrough and Heuristic Evaluation activities were confirmed by the user testing with think aloud process.

8.3.3.1. Registration, Invitations and Log-in

Participant 1 (P1) found ‘Create Care Circle’ to be confusing but saw ‘New User’ as a clearer option. She mentioned that the underline for the entire text ‘New User? Create Care Circle’ was a bit confusing, but proceeded to register. P1 liked the fact that she knew in advance that she would get an email upon registration. She added that it was only because she has a Google mail account similar to the screenshot shown in the visual guide next to the registration. As part of the registration process, P1 typed her

full name for 'Username', which gave her an error message. She guessed it was probably the space between the names, tried again after removing the space and it worked. She read the confirmation that she should check her email for the confirmation and sounded pleased. P1 did not get her email in Gmail but the researcher tested this by sending her a message via the Care circle and she got it. She re-registered through a different email account and received the confirmation. P1 logged in. She said the interface looked like a dashboard. P1 commented that the lock may mean that the page was currently insecure as it is too big and open but was not sure. P1 said the 'photo' chat icon was misleading, as it was probably a video camera.

As soon as Participant 2 (P2) was asked to register, she typed her email and password. Then she realised that she was not an existing user. P2 then clicked on the link to register as new user. She spent approximately a minute reading the instructions and asked what she should do. I asked her to complete the details on the right side, which she did. When she typed her full name as user name, it did not accept the space between her first name and surname. The error message did not have any suggestions to move forward. I had to help her out and ask her to use an underscore. Once she did this, a message indicating confirmation that an email was sent to her email displayed. She tried to access the email from her phone and then said that she may need to click the link so decided to access in a new tab. She commented that the NHS emails usually took several minutes to appear. To allow her to progress with the rest of the activities while waiting for her email confirmation, I logged in under my own details, deleted the care circles I had created and asked P2 to continue with the other tasks.

Participant 3 (P3) clicked on the new user option and typed her details. When she typed her full name for username, it came up with an error message that did not indicate what she did wrong. I asked her to put an underscore between her first and surnames. She received the confirmation by email, which she connected to using her phone, and clicked on the link. Thereafter, she was able to login using the computer.

While creating the Care circle, P1 thought this might be for her but she looked three steps down and realised it was for the child. After creating the circle, she said that she felt like she has created a username for her sister (the child in this case). P2 created a care circle for a child (fictitious) without any problems. However, she clicked on the

‘Create Care Circle’ link three times which created three circles for her. This pushed the contents of the lower part of the screen further down which made it quite difficult for her to view the options at the bottom of the page. P3 started typing her full name and date of birth and also selected that she did not have any children. I made a note that any built-in forms could by default be interpreted as about the user and if it was not the case, it should be clearly stated. I stopped P3 and explained that this was to create the Care circle. She understood and mentioned that it was important to indicate that this was about the child. She then created a care circle for a child she works with. Professional relationships were not available to select as relationship to child and therefore she selected ‘aunt’.

P1 noticed that the ‘invitation’ is the only way to add someone to Care circle. P1 invited me to join the care circle she created. Choosing Invite to Join the care circle responded with a message that said ‘User has not joined a care circle’ She said that she was not sure what had happened and if there would be an option to show that invitation was pending. While she was doing this, she discovered other options on the care circle. P2 was able to search for care circles and People and send invitations and requests to join without encountering any difficulty. When P3 was asked to add a new member to the care circle, she typed a name into the field and clicked the Search button. She said ‘how do I know who’s there?’ Then she realised what was happening and mentioned that the invite and search options should indicate who is being invited. She typed a new email address and sent an invitation.

I added P1 to my care circle. P1 accepted my invite to join a circle. But she looked for how to specify her relationship to my circle and could not find it. New members should be able to see the ‘profiles’ of other care circle members to understand their roles in the care circle. P1 had no comments on this option. When I accepted P1’s invitation, the notification of acceptance was not received. As for P2, the field to type new email was already complete, and she clicked the button to send the invitation first. As P2 was already using my account, accepting invites, registering and joining care circle tasks could not be carried out. I logged into my email and sent P3 an invitation. This appeared in her inbox and she clicked on the notification and joined My Care Circle. She said ‘there it is’ and was quite pleased to see the new care circle added beneath her own. P3 carefully observed both the image and the name of the

user prior to adding them to her care circle. The visible details appeared sufficient. The care circle creator should be notified if he or she should accept the invitation and registers. However, notification of acceptance was not received.

8.3.3.2. Usage

The usage activities included starting and posting on discussion forums; receiving feedback; have text/voice/video chats; use calendar and share files.

P1 was not sure if she should ask all questions publicly. She deleted the default text and then typed a question and submitted it, but there was no response. When P2 was asked to find out information about a child, she navigated to 'Notifications' and stopped as she was unable to continue. I redirected her to the Questions section. She then hit return and typed the question under the existing sentence. When she submitted the question, this did not indicate if the message was sent. So she asked 'what happened?' I told her that it was posted but she couldn't see it. I showed her where it displayed and then we moved on to the next task. P3 interpreted 'Notifications' as where someone would notify a circle of a query. After indicating that she needed to look at 'Questions' she was able to go to the questions section, delete the default text and type a question. After submitting the question, she said 'what happened?' and was unsure what happened to the question as there was no confirmation.

P1 looked for the questions not answered yet and found them. She was not sure if she should look for all questions for all participants or if there was an option for filtering questions. She did, however, respond to the question. P1 mentioned that once again there is no feedback on what she did. P2 expected to be able to click anywhere on the grey button area (instead of just the +) of the Q & A feature and took a few minutes to work out how to navigate. P2 saw the questions and the option to comment on them. When she clicked, the options to respond appeared. One of them was the option to upload an image, to which she commented 'who is that?' The icon used to indicate uploaded images was clearly misleading. She didn't notice the question above this image either. Once again, she hit the enter key and typed her response without deleting the default text. She clicked on 'upload' and then it took her back to the Questions page. Once again, there was no confirmation to indicate that her comment

was posted. She had to be shown where her comment was posted. She commented that as a doctor, she wished it would indicate more clearly that she was expected to respond to questions rather than ask questions. P2 mentioned that NHS staff had to include a disclaimer when giving medical advice on safety, responsibility and reliable advice. P3 carefully scrolled down and read the text on each section and commented that she didn't understand the 'Latest Question' section. She however clicked on the other questions section and was able to comment. Once again, she mentioned that there was no confirmation.

All three participants mentioned there was nothing to indicate that someone has responded to a question.

P1 did not comment on Progress or status updates for/on your child. This was merely an observation and not applicable to P2's profession as a doctor. Nevertheless, P2 commented that it would be nice to have latest status update/summary, for example if there had been a change of medication or assistive technology. P3 had no comments.

P1 mentioned that it would be helpful to know if records of text, voice or video based chat options were stored. The video chat feature was not functional. However, P2 commented that this would be a useful feature to have in case of emergency if an NHS appointment was not available. P3 recommended that an option to disable or sign out of video chat should be added, as she did not like to have video chats that may take up unnecessary time.

P1 was able to share the file of her choice without any problems. P2 mentioned that this was a useful section, but she did not connect its purpose with the title 'Notification'. She kept clicking on the category to be able to upload. She could not upload. I helped her with the upload and she was happy. She recommended that upon clicking anywhere in the grey area the section expanded, and the option to share was made available. This was so she would know if anyone has already uploaded what she was about to upload. P3 was able to share information easily. She commented that a share option for each section may be more useful.

It was not possible to evaluate the functions for following up online assessments, seeing a Calendar with important dates, or viewing previous records of child because the features had not been fully built.

8.3.3.3. Selective access

Due to the lack of existing users, the access details could not be evaluated. However, some general suggestions were made by P2 on these features.

P2 suggested that a disabled but capable adult should be given the option to control his or her own care circle instead of the legal guardian. She mentioned that each individual should be able to restrict questions and answers privacy. P2 commented that she did not need the print option.

P1 and P3 did not have any comments on the selective access components.

8.3.3.4. General feedback

P1 mentioned that the chosen shade of pink was too ‘loud’. Users are not always children and the site could look more mature. Having an option to register via an invitation, and not needing to start from the beginning might be preferable if a user is invited into a care circle directly.

P2 said that this would be a supportive tool and save a lot of time if the technical problems were fixed, and she herself would encourage families she works with to use it.

P3 said that this would be a useful tool for some of the children who she works with.

8.3.4. Summary

Activity 18, User Testing was intended to *evaluate* the interface from the perspective of real users, to produce data on the usability of My Care Circle.

- *Beneficiaries*
 - B23: NHS staff have to include a disclaimer when giving medical advice on safety, responsibility and reliable advice.

- *Evaluation*
 - E8: Three care circle members tested Version 1 of My Care Circle and provided feedback for improvement.
- *Artefact*
 - A46: Provide a status update to indicate and changes to medication or AT
 - A47: Inform users if text/voice/video conversations are stored
 - A48: Disabled but capable adults should be able to control their own care circle.
- *Purpose*
 - P15: Video chat could be useful in the absence of NHS appointment for emergencies.

In addition to new *artefact* features, *purposes* and *beneficiaries*, bugs and implementation oversights were identified and usability problems of the features were assessed. The task list introduced at the beginning of this chapter is once again used to summarise these findings on usability.

8.3.4.1. Registration, Invitations and Log-in

1. Register on MCC
 - a. Registration should be with full name and email: several problems encountered in the registration process, particularly relating to user name, need to be fixed.
 - b. Login afterwards should be by typing your email and password: straight forward and clear.
2. Create care circle
 - a. Complete profile: generally confusing as to who the profile is for.
 - b. Select Relationship to the cared for from drop down: clear, but picture upload confusing.
3. Invite new members to MCC
 - a. Existing users: users would like status of invitations and notifications to be clearer.

- b. New users: process is clear, but legal guardian should be able to see basic profile prior to adding someone.
- 4. Care circle member
 - a. Accept invitation: feature is functional
 - b. Register: This process needs to include a notification.
 - c. Join care circle: The steps taken to complete the task can be simplified.
- 5. The 'new' member should be able to see the 'profiles' of other care circle members: This is not currently possible.
- 6. The care circle creator should be notified of activities within the care circle and he or she should accept the registration: This was not available.

8.3.4.2. Usage

1. Start discussions on forums: Sign posting via 'Notifications' was confusing. No notification of activities.
2. Contribute to discussions on forums: Feature is functional but there needs to be better notification options for when someone posts something. Navigation needs to be clearer.
3. Receive feedback on queries about child concerned: Notifications need to be included.
4. Progress or status updates for/on your child: not evaluated
5. Have text, voice or video based chat options where records are not held: The feature needs to be developed. In addition, it would be helpful to know privacy details.
6. Follow up online assessments: not evaluated
7. Calendar with important dates: non-functional
8. All users should be able to share files with helpful information: clear, except for who it can be viewed by and the lock icon.
9. Should be able to view previous records of child: not evaluated.

8.4. Activity 19 – Demonstration and Reinforcement Study

As it was over three years since the initial Activities 1-8 were recorded in Chapters 4 and 5, it was appropriate to check if the findings were still applicable. With this focus,

a special needs school for cognitively impaired children was contacted. The aim of the activity was to triangulate, reinforce and extend findings. However, it will also be receptive to any contradictions to previous activities.

8.4.1. Participants

This was a school for children with behavioural problems. A majority of these students had diagnosed conditions such as Autism, Asperger's Syndrome, Attention Deficit Hyperactivity Disorder (ADHD), Attention Deficit Disorder (ADD) and other learning disabilities such as Dyslexia and Dyspraxia. There are 71 boys and five girls in the school in years 1-5. There were eight students in each class.

The Deputy Head Teacher (DHT) provided a tour of the school and gave some background to the school. I spent time with three different classes including discussions with the class teachers.

8.4.2. Method

An explanation of the research and the purpose of visit was given via email ahead of the meeting. The schedule included a demonstration of My Care Circle (MCC), observation and participation in the school's activities, opportunistic interviews and surveying (using the survey from Chapter 6) if possible.

8.4.3. Findings

One of the causes for behavioural problems is reported as undiagnosed or delayed diagnosis of disabilities. Children at this school are supported for special needs and behavioural problems. Compared to the school, mentioned in Activity 1, this is a different type of special needs school where there are special behavioural and emotion management techniques practiced. Appreciation for things and people, self-respect, respect for others, team-work and not criticising weaknesses are some examples of the characteristics that are nurtured.

Some of the in-class support for managing learning difficulties included using a dictionary and thesaurus, reading support skills, managing ADHD behaviour over meals and other times when children had to wait (eg. Waiting in a line to go to play).

The DHT mentioned that the biggest challenge for the school, particularly for children with complex needs, is that they do not get similar guidance at home. The parents are not aware of how to bring up their children. She also spends a lot of time sending emails, letters and talking over the phone to parents to explain the support.

A demonstration of MCC was given for the DHT.

- She liked the site and commented that it would help centralise information;
- It would reduce her time spent on repeating information to parents.
- She recommended that it would also help communication with Social Workers
- An alert system for any unusual behavioural management issues would be helpful
- The site would be more helpful to children with complex needs, compared to those with diagnosed and managed disabilities;
- The recent coalition government (2009-2014) is withdrawing the policy on mandatory inclusive education for all children diagnosed with disabilities, which was in place when the research started (referred to in Activity 1), and granting access to special needs schools to children who need it.
- DHT would be interested to see the MCC once update has been completed.

The DHT also completed the questionnaire for professionals used in Chapter 6, and the summary of findings listed according to the question number is as follows:

1. She works with children ages 5-11;
2. She believes the care circle membership should be in the region of one to five: "SALT Carer, Parent, TA, LACAT, EP, Autism Advisory teacher, PD service, CAMHS professionals, Teacher";
3. She uses Email, forums and discussions online to communicate;
4. She uses telephone at least weekly; Emails 1-2 times a month; Letters 1-2 times a month; Homework book weekly; meetings 1-2 times a month; onsite training 5-10 times a year; Never uses SMS or social networking;
5. She is likely to look online for information;
6. DHT believes peer networking to be very important;
7. She thinks current ways of communications are Okay;

8. DHT agrees that current communication is ‘timely’, ‘helpful’, ‘regular’, ‘empathetic’; felt neutral about ‘flexibility of alternative’;
9. She thinks any new solution must be at least as empathetic, regular and timely as existing solutions;
10. DHT disagreed that the current communication was ‘Reluctant’, ‘Abrupt’ and felt neutral about ‘Ambiguous’ and ‘Patronising’ as listed in the questionnaire;
11. DHT felt the most important qualities of the solution would be access, support and clarity;
12. She accessed the internet several times a day;
13. DHT believed off-the-record conversations are very important, to allow for communication to be as open as possible;
14. She would use MCC to discuss education, therapy and assessments;
15. She was interested in the following features of MCC: progress updates for/on your child, follow up online assessments, the ability to view previous records, the option to choose the information to be shared with each member of care circle, the calendar, and the option to print copies of discussions;
16. Her concerns included privacy and security and any possibility of additional demands on her time due to using MCC;
17. DHT did not wish to be contacted for future participation.

8.4.4. Summary

Activity 19 confirmed existing findings specific to care circles about *beneficiaries*, *purpose* and *artefacts* and also extended the list as follows:

Beneficiaries:

- B24: Should include behaviour related care circle members such as psychologists;

Artefact:

- A49: A warning or alert system for emergencies and behavioural management issues was recommended;

Purpose:

- P16: An alert system to flag any unusual behavioural management issues;

- P17: Reduce time spent writing and emailing individually by sharing information online with all carers.

This activity was *performative* during the demonstration and *inquisitive* when information was elicited. This activity was *protective* holistically as it was affirming the continuing relevancy of the artefact. The activity was *invigorative* in assuring that the artefact was still relevant and also met additional purposes. The findings were *informative*.

8.5. Summary of Iteration 5

The aim of Chapter 8 was to *evaluate* the first version of My Care Circle, triangulate and possibly extend the findings from previous findings relating to *purpose*, *beneficiaries* and *artefact*. The evaluation was conducted by: Cognitive Walkthroughs using the three personas created in Chapter 7; Heuristic Evaluation by the researcher and an experienced web developer; and the user testing by three members of the care circle. Most of the findings related to providing clearer instructions to the user and providing feedback on tasks completed. Users also needed some assurance on privacy.

As anticipated with Heuristic Walkthrough, there is a possibility that bias may have developed with the findings from the Activity 16 (Cognitive Walkthrough using Personas) influencing the next Activity 17 (Heuristic Evaluation) as they were both conducted by the researcher. When instructions were provided in Activity 18, a conscious attempt was made to provide the same instructions and guidelines to each participant to be able to compare responses without bias. Tasks were in written form and the evaluation of findings was completed once all findings were collected. This corroborated and extended the heuristic walkthrough process.

The reinforcement study was conducted in a Special Needs School and included observations, participation in activities, demonstration on site and completion of questionnaire. This entire evaluation process provided information pertaining to artefacts and Activity 19 pertaining to purpose. It also extended the *beneficiaries* list.

8.6. Reflection on Iteration 5

This iteration of Research through Design focused on the evaluation of the *artefact* and the confirmation of purposes in DAP lists from Iterations 1 and 2. This involved four primary research activities. This process was generally sequential as the researcher carried out all activities.

8.6.1. Order of Activities 16-19

The researcher conducted an Extended Cognitive Walkthrough and Expert Heuristic Evaluation over the month of October 2011 and the User Walkthrough was planned in August 2011 and completed in November 2011. The analysis of the findings took longer than the actual elicitation of data. All feedback was forwarded to the developer together with recommendations for amending the issues identified in the feedback as soon as was practical. The demonstration and reinforcement study were conducted over a day in January 2012. The redesign and development of Version 2 of took a further six months and was completed in August 2012. There was continuous feedback and evaluation during this process as recorded in Chapter 9.

Table 8.1 - Order of Activities

Chapter 8 - Evaluation and Redesign	
August 2011	Activity 16: Plan user based evaluation
October 2011	Activity 17: Heuristic Evaluation
November 2011	Activity 18: User Based Evaluation
January 2012	Activity 19: Demonstration and Reinforcement Study
August 2012	Site Version 2 -built

Apart from Activity 19, which took place while the redesign and development was going on, the Activities were conducted in sequence (although planning of Activity 18 was conducted at the same time as Activities 16-17).

8.6.2. Scope of Iteration 5

The purpose of Chapter 8 was to evaluate the first version of MCC thereby making the focus on *evaluation*. This is co-ordinated with the *beneficiaries* using personas and the heuristic walkthrough, *artefact* in their usage and *purpose* in the demonstration and reinforcement study.

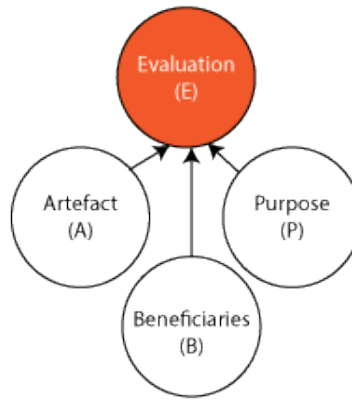


Figure 8.1 - Most Abstract Design Situation (MADS) of Chapter 8

The findings related to all four *design arenas* as expected (Figure 8.1).

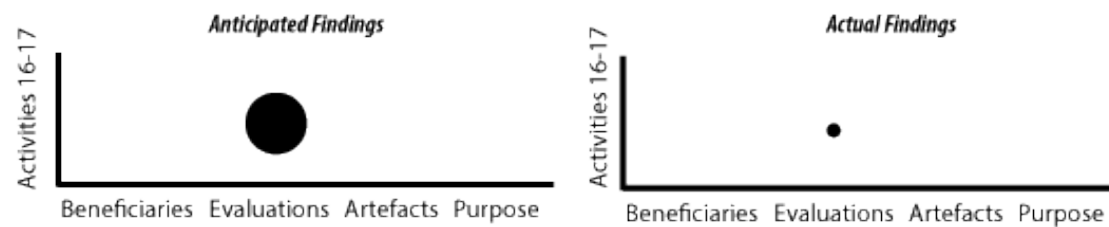


Figure 8.2 - Proportional Abstract Design Situation (PADS) of Activities 16-17 – Cognitive Walkthrough and Heuristic Evaluation

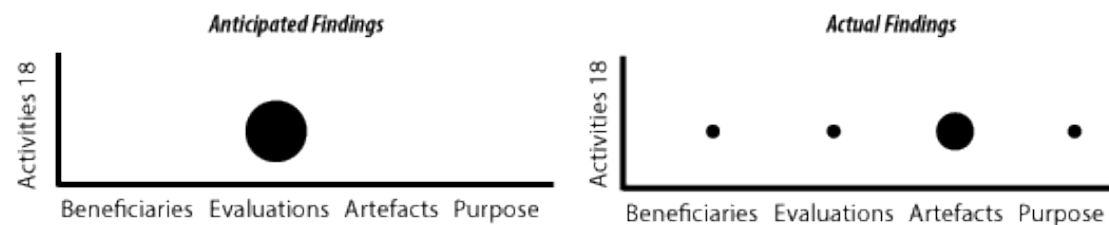


Figure 8.3 - Proportional Abstract Design Situation (PADS) of Activity 18 – User testing with Think Aloud

Activity 19 evaluated the relevance of the artefact and the findings confirmed it was still relevant. In addition, it extended the *beneficiaries*, *artefact* and *purpose*.

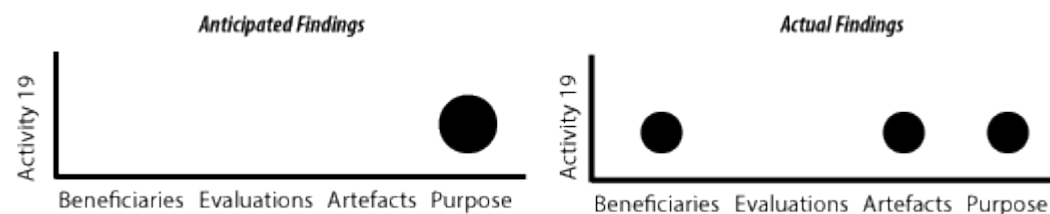


Figure 8.4 - Re Proportional Abstract Design Situation (PADS) of Activity 19 – Reinforcement Study

The continuous redesign and evaluation of the artefact is recorded in the next iteration in Chapter 9.

8.6.3. Progress in Iteration 5

The first evaluation of the actual system took place in Activities 16-18 and the artefact was revised. This evaluation was conducted with the least risk by the researcher using personas, web experts and three independent care circle members. Also, no data pertaining to real disabled individuals were used in the evaluation. Activity 19 also confirmed the suitability of such an artefact for the purpose and beneficiaries identified in the previous activities.

The conclusion from this iteration are as follows:

- MCC as an artefact needs to improve both in functionality and design for independent usage.
- Despite its problems with functionality and usability, users find MCC to be a beneficial design solution for the chosen design problem.
- An informative and collaborative social support system MCC continues to be a relevant design solution.

This iteration shifted the design from an implemented artefact to an evaluated one. In this process, the beneficiaries' involvement became continuous. Activity 19 also extended involvement of beneficiaries. While in Iteration 3, functional testing was done by the researcher and feedback provided to the developer, Iteration 4 extended this evaluation. The artefact also shifted from Version 1 to Version 2.

Table 8.2 - Shift of Design Arenas in Iteration 5

	<i>From</i>	<i>To</i>
<i>Beneficiaries</i>	Involvement of both professional and personal Personas.	Continuous and additional involvement of both professional and family members of the care circle
<i>Evaluation</i>	Functionality testing was done to provide feedback to developer.	Evaluated social network and information system, for usability, adequacy and desirability.
<i>Artefacts</i>	Finalising requirements for the social networking system. Completed first version of development.	Evaluation and redesign of artefact.
<i>Purpose</i>	Confirming worth centred	Purpose confirmed and

	<i>From</i>	<i>To</i>
	user needs for the artefact by checking against the personas.	extended by potential users.

8.6.4. Resource Functions Analysis

All activities were *inquisitive* as they elicited information and *protective* in that they tested the artefact using personas and heuristics evaluation by experts. The demonstration of the website was *performative*. The findings were *informative* and *expressive* as seen in Table 8.3.

Table 8.3 - Realities of Resource Functions in Iteration 5

Chapter 8	Resource	Achieved Functions
Activity 16	Cognitive Walkthrough	Inquisitive, Directive, Informative, Protective
Activity 17	Heuristic Evaluation	Inquisitive, Directive, Expressive, Informative, Protective
Activity 18	Usability testing	Inquisitive, Informative, Performative, Expressive
Activity 19	Demonstration (Reinforcement Study)	Inquisitive, Informative, Invigorative, Performative
Activity 19	Tour and brief observation (Reinforcement Study)	Inquisitive, Protective, Informative
Cumulative Function		Informative and Protective

Collectively, the findings from these resources were *protective* prior to being released to a wider user group and was *informative*.

8.7. Next Iteration

This chapter reported the evaluation of Version 1 of the *artefact* and recommendations for the development of Version 2. Evaluations were conducted using personas, experts and users to provide a well-rounded response. A special needs school was chosen for an additional study to triangulate and possibly extend the *purpose, beneficiaries* and *artefacts* and whether it was still valid for the research. The findings were consistent with Iterations 1-3 and the study added value to the research by producing complementary findings. The next step was the development of Version 2 of MCC.

This iteration showed a shift in the understanding of beneficiaries, artefact requirements and purpose over a variety of evaluations. The focus of the next iteration is to evaluate the redesigned artefact.

The next chapter reports on continuous feedback, minor development and reflection on the entire research through design process and has several design arena co-ordinations. Activity 20 is anticipated to be evaluative as it is co-design of content

and evaluation plan and informative of what content to add. Activities 21-23 are expected to be evaluations of MCC.

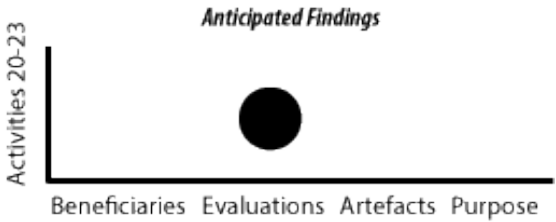


Figure 8.5 - Anticipated Proportional Abstract Design (PADS) Situation for Iteration 6

This iteration is intended to end the study and lead to defending the claims. The anticipated shift in design arenas in Chapter 9 is as shown in Table 8.3.

Table 8.4 - Anticipated Iteration Shift for Chapter 9

	<i>From</i>	<i>To</i>
<i>Beneficiaries</i>	Continuous and additional involvement of both professional and family members of the care circle	Improved support for care circle members and increased capability of individuals with disabilities.
<i>Evaluations</i>	Evaluated MCC, for usability, adequacy and desirability.	Re-evaluated MCC
<i>Artefacts</i>	Evaluation and redesign of artefact.	Effective artefact that is in usage.
<i>Purpose</i>	Purpose confirmed and extended by potential users.	Continuously meets identified and evolving purposes.

Chapter 9 – Iteration 6: Further Evaluation and Development of Artefact Version II

Based on the findings from Iteration 5, especially since the developer's design skills were identified as poor, recommendations together with detailed screen designs redesigned by the researcher (examples in Figure 9.1 and 9.2 and remainder in Appendix C9 – Screen Designs) and a logo were provided to the developer who redesigned the website, My Care Circle (MCC).



Figure 9.1 - Version 2 Screen Design



Figure 9.2 - Profile Page Screen Design

As a result of the feedback provided, relating to feeling comfortable about who you share information with, at each point on the site where there is interaction, a clear notification of who can see the files was included. An example can be found in Figure 9.3.

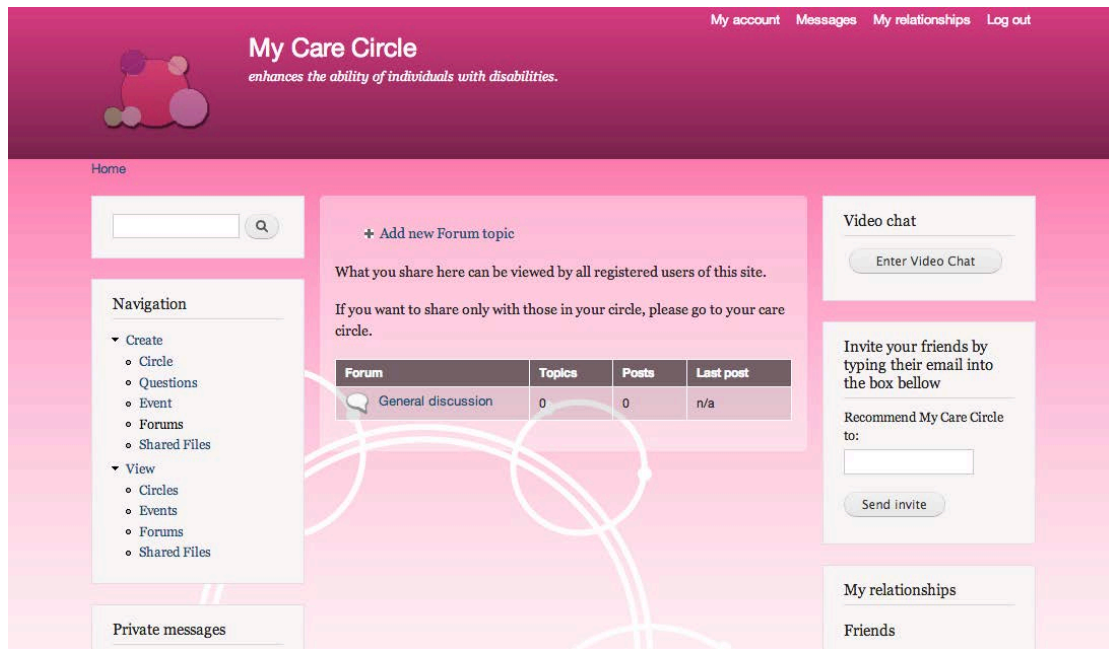


Figure 9.3 - Privileges Notification

This chapter starts by recording the plan for evaluation in detail. It then records the evaluations that were carried out and subsequent developments. As will be evident from this chapter, the evaluation did not proceed as anticipated. Therefore, alternative multiple triangulated evaluations were conducted instead. This chapter discusses potential reasons for why the plan did not work, and reports the evaluations that were carried out instead. The chapter concludes by discussing the impact of these evaluations on the research claims.

9.1. Activity 20 – Co-Design and Evaluation Plan

The redesign of Version 2 of MCC in Chapter 8 was ready to be opened to participants from the general public. However, a social environment needs information and conversation that members engage with, and therefore an empty or unpopulated social network cannot be used. This led to the decision to carry out co-design to populate the site information.

Ethical approval had been obtained previously for user testing. This approval was extended to cover co-design with member a of NHS and opening the website to complete care circles.

ssStep 1: Co-design design session with Dr Mary Akinola, a GP from the NHS

A demo of my care circle was presented to Dr Akinola, who was a participant and evaluator of the first version of the site. She requested an introduction to the website MCC, and information on the physical conditions of potential participants, and environments in which the site might be used, to help identify support material that could be included in the site.

Dr Akinola agreed to collect information from the NHS that could help meet task demands in the following categories which were also agreed with Dr Akinola:

- Assessments
- Assistive Technology
- Care and Hygiene
- Education
- Entertainment
- Funding Assistance
- Psychological Needs
- Support for Carers
- Therapy
- Technical Support for AT

Once there is sufficient information in the platform to address at least three different types of physical conditions, it would be made open to the users.

Step 2: Participant Recruitment

Participants were to be recruited from personal contacts, including those who contributed to the earlier questionnaire, and those professionally recommended by Dr Akinola for a trial period of six months.

The process of usage was to be as follows:

1. Registration of user
2. Creating a care circle for each disabled individual by:
 - 2.1. Adding details to their profile such as description of special needs, AT devices, environments where support is required;

- 2.2. Inviting family members, medical professionals, educators or other parents or carers of similar individuals or whomever they think fit to be members.

Step 3: Active usage

Participants were then to use the web platform to:

3. Communicate via private messages, restricted and public forums and video chats;
4. Provide continuous support thereby reducing expensive assessment;
5. Create and keep track of events;
6. Share information.

For two months, a fortnightly guide with tasks was to be provided to each care circle to encourage usage. With the care circle's permission, I was also to be a member of the circle during the trial period.

Step 4: Results

As I was both introducing the tasks and an active participant, there was a likelihood of bias. However, without a pre-populated platform or the introduction of tasks, there may be no usage. To identify the impact of this bias, a survey will be conducted at the end of the study.

The survey will be conducted with the participants of the study and will measure how the artefact has improved the situation identified through the questionnaire in Iteration 3, Chapter 6. Worthwhile outcomes and adverse outcomes measured can be seen in Table 9.1.

In addition, being part of the care circles will enable me to conduct observations of:

- engagement frequency and
- nature of engagement;

Data from the message content will be used to:

- identify purpose of communication;

- engagement and
- problem solving.

Google analytics will be used to identify:

- the type of device used to access the website, whether mobile or fixed to understand whether portable usage would be beneficial and
- location from where the website is accessed.

Ethical considerations relating to data protection were managed as follows:

- Online data will be stored for as long as the website is active.
- Participants have the right to delete data or close their account at any time after signing up.
- The developer has administrator access for development of the website and data. I have an administrator access to verify details of registered users. However, I cannot join or participate in a care circle without the authorisation of the legal guardian.
- There is a twelve-month maintenance agreement between myself and the developer that has now expired. The developer was to access personal data only if participants reported a related technical problem to me.

Table 9.1 –Worth Element Measurement Table

Worthwhile outcomes	Instrument of measurement	Adverse Outcomes	Instrument of measurement
a) More frequent engagement of more care circle members	<ul style="list-style-type: none"> Record of communication Usage Tracking Compare with questionnaire data 	a) Few care circle members frequently participate	<ul style="list-style-type: none"> Record of communication Usage Tracking Compare with questionnaire data
b) More rapid improvements on child's personal, social and environmental factors	<ul style="list-style-type: none"> Survey (parents and professionals) 	b) Lack of impromptu tips and tricks from peers for child's lifestyle	<ul style="list-style-type: none"> Tracking content
c) More appropriate and timely support by more members of care circle	<ul style="list-style-type: none"> Survey (parents and professionals) 	c) More appropriate and timely support by more members of care circle	<ul style="list-style-type: none"> Survey (parents and professionals)
d) Improved communication	<ul style="list-style-type: none"> Survey (parents and professionals) 	d) Breakdown in communication between school and parents as child struggles to communicate	<ul style="list-style-type: none"> Survey (parents and professionals)
e) Better informed life style support	<ul style="list-style-type: none"> Survey (parents) Analysis of uploads and downloads 	e) Waste time repeating information and miss out on receiving possible useful information	<ul style="list-style-type: none"> Survey (professionals) Logging downloads and uploads
f) Don't feel isolated	<ul style="list-style-type: none"> Survey (parents) 	f) Feel singled out and just another child (instead of unique and special)	<ul style="list-style-type: none"> Survey (parents)
g) Better, flexible AT support	<ul style="list-style-type: none"> Survey (parents and professionals) 	g) Little and even no technical support for AT devices	<ul style="list-style-type: none"> Survey (parents and professionals)
h) More frequent and accurate assessments	<ul style="list-style-type: none"> Record of communication Compare with questionnaire data 	h) Assessments are bi-annually or annually: children grow fast	<ul style="list-style-type: none"> Record of communication Compare with questionnaire data

Worthwhile outcomes	Instrument of measurement	Adverse Outcomes	Instrument of measurement
i) Reliable information ready to hand	<ul style="list-style-type: none"> Survey (parents) 	j) Difficult to identify reliable sources and readily available information	<ul style="list-style-type: none"> Survey (parents)
k) Important documents and forms ready to hand	<ul style="list-style-type: none"> Survey (parents) 	m) Only hardcopies available from specific sources by special permission	<ul style="list-style-type: none"> Survey (parents)
n) Shared specific information is independently accessible	<ul style="list-style-type: none"> Survey (parents) 		

- While the online data will remain in a secure server for as long as the website is live or the user chooses to close the account, other digital notes or copies made to evaluate the data will be kept in a password protected personal laptop until the end of the PhD and any relevant publications and thereafter destroyed.

Step 5: Evaluation

The worthwhile outcomes and adverse outcomes identified in the Worth Sketch Version 3 (Chapter 6) would be used to measure costs and benefits of the study. The methods that it was anticipated would be used to assess them are listed the Table 9.1.

Further, any worthwhile and/or adverse experiences shown in the Worth Sketch that were not addressed in the worthwhile/adverse outcomes would also be recorded.

The worthwhile experiences to be evaluated are as follows:

- Manageable schedules
- Dependable knowledgebase
- Satisfactory service
- Confident communication
- Reduced stress
- Motivated users
- Moral support
- Reduced time and travel demands
- Empathetic environment
- Convenience

The adverse experiences to be evaluated are as follows:

- Fewer decision makers
- Delays in receiving support and advice
- Annual assessments
- Poor communication between professionals and families
- Too many methods of communication
- Isolation

- g) Insufficient tech support
- h) Poor off-site support
- i) Inconsistent, unreliable or no information
- j) Inflexible solutions

This data was to be used to revise the worth sketch and conclude this research.

9.1.1. Co-design of Content

A demonstration of MCC Version 2 was made to Dr Akinola who responded to the questionnaire recorded in Chapter 6 and was also a participant in the User Walkthrough in Chapter 8 (Activity 18). As per her request, based on the personal contacts that showed interest, I provided the disability categories as Autism, Cerebral Palsy, Dyslexia and Down's Syndrome. I also requested information on assessment processes, funding and screening.

She provided me with information and useful official websites used to support individuals with the relevant disabilities at both diagnosis and for on-going management of their conditions as part of co-design.

The platform was pre-populated with details for the Shared File section, which was the repository for information in the various categories as shown in Figure 9.1.

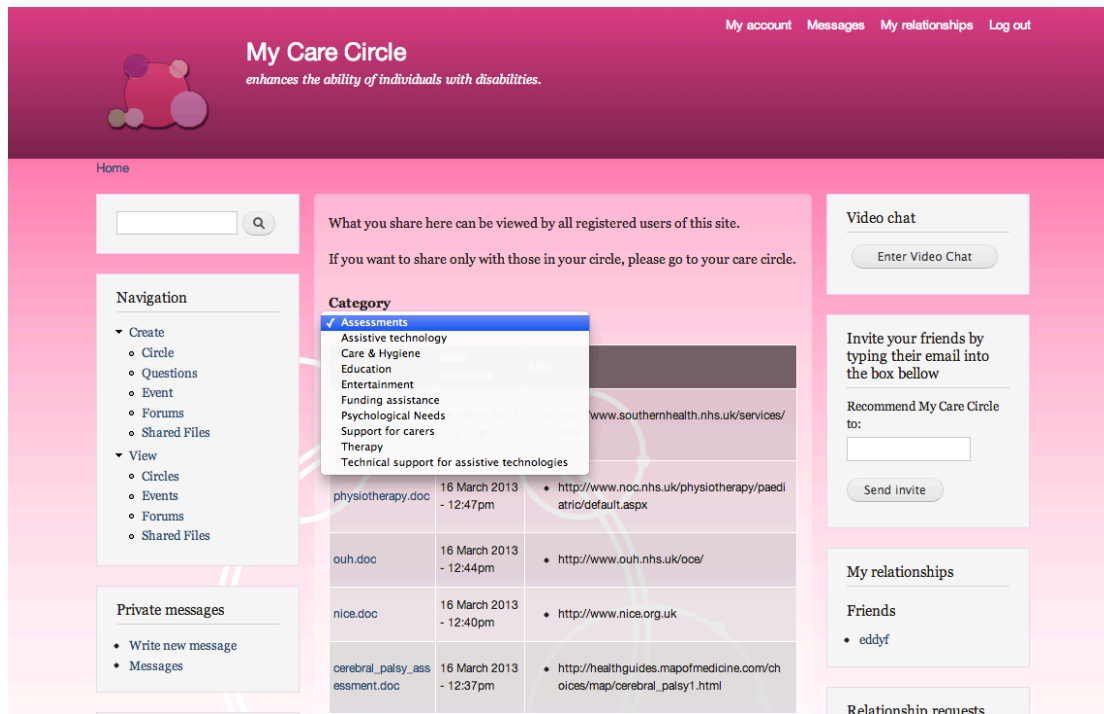


Figure 9.4 - Shared Files

9.1.2. Participant Recruitment

Participants were a mixture of personal contacts, including those who contributed to the earlier questionnaire, and those professionally recommended by Dr Akinola in the co-design.

Six individuals joined the care circle. Each of them provided feedback at various times based on which amendments were made. However there were also frequent challenges which produced findings. This feedback and the new findings arising from it are recorded in the following sections.

Activity 20 helped prepare MCC, the *artefact*, for *evaluation* with a potential *beneficiary*. The activity was *directive* and *protective*.

9.1.3. Summary

Activity 20 was primarily *directive* as it organised and co-designed content, planned usage and *evaluation* of MCC Version 2, the *artefact* with real *beneficiaries*. There were no specific findings from this activity. This activity was also *protective* in planning the measurements.

9.2. Activity 21 - Qualitative feedback from Independent Usage

The first feedback obtained was from a participant recommended by Dr Akinola.

9.2.1. Participant

The participant was a parent of a disabled individual and was a patient of Dr. Akinola.

9.2.2. Method

Dr Akinola recommended MCC to a carer who used the site and provided written feedback (see Appendix C9 - Feedback from Independent Usage). A summary of the feedback is as follows:

9.2.3. Findings

The positive comments from the participant were as follows:

- It would help with travel difficulties owing to motor disability, bad weather or in remote areas where there is no access to support;
- It would be helpful to support children who have active social commitments;
- The words ‘support’ and ‘share’ are comforting;
- It makes friendships possible for those isolated due to disabilities;
- It could be a great recovery promoter for those who are generally low or lonely;
- It could be a stimulus and activity when carers are pre-occupied.

The concerns raised by the participant, which could be potential risks to recruitment and usage were as follows:

- Some may have funding issues that would prevent them having a computer or internet connection;
- Professionals may not be keen to share their own tasks with other members of the care circle due to ethical guidelines, codes of conduct or confidentiality;

- If users have had bad experiences in the past, they may not be willing to share personal information within care circle;
- This may be a scientific study or research and not be of benefit to them.
- People may continue to prefer face-to-face contact;
- Peers may make recommendations with good intentions but suggestions may be harmful.

9.2.4. Summary

Activity 21 was primarily *inquisitive*. The findings from this activity were *informative* as the participant documented her views.

Beneficiaries

More detail was identified about already identified care circle members.

- B25: They may be unable to afford technology;
- B26: Professionals may not be keen to share professional practice informally;
- B27: Users may have had bad experiences in the past with new networks and may not wish to try again;
- B28: People may prefer face-to-face contact;
- B29: People may think the artefact may be for research only and not continued use and may wish to avoid participating.

This feedback however confirmed that the *artefact* could meet the needs of *beneficiaries* and associated *purpose*. It also suggested why some users may be hesitant to use MCC despite it being a useful solution.

9.3. Activity 22 - Feedback from Assessment Centre

The Centre from Activities 1 and 7 was contacted for a demo, feedback and potential recruitment.

9.3.1. Participants

The participants in the demo and feedback were a Service Delivery Assistant (SDA) and two AT Specialists, one of who was a Speech and Language Therapist (SLT) in Activities 1 and 7.

9.3.2. Method

A total of 90 minutes were spent on this activity. Since two out of three participants were not aware of my previous involvement with the organisation, Activities 1 and 7, discussions about complementary work to SpeechBubble, or a background of the research and an introduction to my previous involvement with the organisation was provided. The Centre had between my Activities 1 and 7 and this activity, relocated, restructured and had several new projects. This was followed by an explanation of the Worth Sketch Version 3 and a walkthrough of MCC Version 2.

9.3.3. Findings

The participants raised questions relating to the genuineness of care circle membership, e-safety, and the purpose of various sections and notifications. They were satisfied with the work that had gone into addressing all of these concerns.

The participants requested that a dummy circle be set up for their use, which was provided. They commented that the NHS may not permit sites of this nature to be used from within their premises.

Participants complemented on the multi-way video chat and the way the tool bridges the gap between bureaucratic procedures and personal needs by allowing for time savings.

Participants recommended a registered charity, 1Voice (<http://1voice.org.uk/>) where there would be ready made care circles who may be able to use mycarecircle.co.uk.

The SDA agreed to investigate if this programme could contribute to the next version of the SpeechBubble project (referred to in Activity 1). However, upon follow up she confirmed that the scope of the next version of SpeechBubble was already defined and this would not be possible.

The participants commented they hoped this project continued beyond this research.

9.3.4. Summary

The activity started with a *protective* and *performative* demonstration and was *inquisitive* by nature. The feedback from the activity was *informative*. The feedback session at the Centre confirmed that the *artefact* met the needs of *beneficiaries* and associated *purpose*. In addition to re-confirming most of the information, there was one additional information on *beneficiaries* was identified.

Beneficiaries

- B30: The NHS was identified as a potential stakeholder who may not permit usage of MCC.

9.4. Activity 23 - Feedback from recruited care circle members

The recruitment of participants for this activity had a low take up, the potential reasons for which are described in Section 9.6. Three participants joined the site.

9.4.1. Participants

From personal contacts three participants who are named as My Care Circle Members (MCCM) 1, 2, 3-6 agreed to sign up.

9.4.2. Findings

Findings from the participants are as follows:

MCCM 1: Following signup, MCCM1 asked how this would be different to Google groups. An explanation of the site and its focus and features was provided. MCCM1 was satisfied but mentioned that while she was convinced of the site's potential, she struggled to invite and convince others to join her circle since the users had to use the site for a while before experiencing any benefits. Upon her request, an information leaflet to help recruitment was also provided in both print and digital formats.

MCCM 2: MCCM 2 was keen to join. She had some difficulty logging in and had to reset her password and therefore she eventually gave up.

MCCM 3 - 6: MCCM 3 created a circle for his friend and also invited three further members (MCCM 4, 5 and 6) to join. Due to work commitments and also feeling as though he was initiating the entire care, he did not continue participation. The topics that were discussed while he was using the website were related to care of his friend, the disabled individual including rehabilitation, sleeping, meals and a special phone for motor dexterity challenges. This confirmed that the purpose relating to the information repository and Q & A discussions were relevant and could be potentially beneficial.

9.4.3. Summary

This activity was *inquisitive* and the findings were *informative*. There were no new findings for *beneficiaries*, *artefact* or *purpose* but there were confirmation of *purposes*. New findings on the *artefact* from the *evaluation* are as follows:

Artefact

- A48: Members of the care circle need to see benefits as soon as they start using the site and not be entirely reliant on self-generated benefits by taking part. The benefits of the site need to be more straightforward and convincing to new users;
- A49: The legal guardian is expected to set up the profile for the disabled individual and start building the circle. This makes the success of My Care Circle somewhat reliant on the legal guardian.

9.4.4. Response to Feedback

As a response to the feedback provided, an information leaflet was created to support care circle members whilst they were being recruited. A thorough check of all log-in and passwords was conducted to see if there were any technical issues that may have contributed to the reaction from MCCM 2. None were identified.

9.5. Worth Element Measurement and Worth Sketch Version 4

The worthwhile outcomes and adverse outcome identified in the Worth Sketch Version 3 were to be used to measure costs and benefits of the study as shown in

Table 9.1. Based on the feedback received in Activities 22 and 23, the worthwhile experience and adverse outcomes were assessed. Any worthwhile and/or adverse experiences and outcomes that are not assessed or addressed in the worthwhile/adverse outcomes were also recorded (Tables 9.2-9.4).

Table 9.2 –Worth Element Measurement Status

Worthwhile Outcomes	Status
a) Manageable schedules	Not assessed
b) Dependable knowledgebase	Professionals have provided dependable knowledge. However, there is no evidence if advice from peers would be dependable.
c) Satisfactory service	Not assessed
d) Confident communication	The Centre commented this would reduce time spent explaining or repeating information and increase effectiveness of communication.
e) Reduced stress	Not possible to say as additional tool to use might increase stress while the actual outcome may decrease stress.
f) Motivated	Individuals who understand the platform are motivated to use it, However, they are struggling to motivate other members to join and use.
g) Moral support	Confirmed over feedback by independent user who provided written feedback (Activity 21).
h) Reduce time and travel demands	Confirmed by both independent user and the Centre.
i) Empathetic environment	Not possible to assess.
j) Convenient	At this stage it appears to be inconvenient as an additional thing to do. However, if usage increases, this is likely to change.

Table 9.3 – Element measurement Table for adverse Outcomes

Adverse Experience	Status
a) Fewer decision makers	Not possible to assess.
b) Support and advice delay	This situation has been improved in the only care circle that had any activity.
c) Assessments only annual	The Centre confirmed that this tool would provide intermediary solutions for this.
d) Poor communication between professionals and family	The Centre confirms that this tool would provide intermediary solutions for this.

Adverse Experience	Status
e) Too many methods of communication	The Centre confirmed that this tool would provide intermediary solutions for this.
f) Feel isolated	The Centre and independent user in Activity 20 confirm that this tool would improve this.
g) Insufficient tech support	No feedback on this. However, the functional care circle raised an AT related question which shows support can be obtained more broadly.
h) Poor off-site support	The Centre confirms that this tool would improve this.
i) Inconsistent, unreliable or no information	The Centre and an independent user confirm that this tool would improve this. Independent user was also concerned about unreliable information from peers.
j) Inflexible solutions	The Centre and independent user confirm that this tool would improve this.

This data was used to revise the Worth Sketch and create an up to date snap shot of achieved worth (Figure 9.3).

The situation is not entirely ideal, however adverse outcomes have been reduced from 10 to 6 where b was replaced by a new risk where risks from peer support is recognised. Adverse outcomes d, one of the gs, h and both js were also removed.

Worthwhile outcomes have increased from 11 to 14 where f, g, h and j have additions and previously separate j have been merged. They are: recovery support from home; increased moral support and inclusion of immediate cheaper assessment.

These changes have been highlighted in green double lines. There were no changes to materials or features.

Worthwhile Outcome	a. More frequent engagement of more care circle members	b. More rapid improvements individual personal social and environmental factors	c. More appropriate and timely support by more members of care circle	d.g. Improved communication	e. Better informed life style support	f. Don't feel isolated; potential to make friends; f. Recovery support from home;	g. Better, flexible AT support g. Increased moral support;	h. More frequent and accurate assessments	j. Reliable information ready to hand; j. Important documents and forms ready to hand	k. Shared specific information is independently accessible
Worthwhile Experience	a. Manageable schedule	b.e. Dependable knowledgebase	c. Satisfactory Service	d. Confident communication	e. Reduced stress	f. Motivated	g. Moral Support	h. Reduce time and travel demands	i. Empathetic environment	j. Convenient
Qualities	a. Flexibility of time and distance	b.c.g.i. Effective & efficient	d. Accurate & reliable	e.g.i. Informative & helpful.	f.g. Caring, encouraging, motivating	h. More frequent help	j. Technically accessible			
Features	a. Live & Synchronous participation	b. Platform where any care circle member could respond	c. Frequent and continuous assessment	d. Professionals and fairly regular communication.	e.i. Support services	f. Know who is the individual's care circle	g. AT support from developer and peers	h. Video and/or self-help therapy	j. Available for download	
Materials	a.g. Chat, discussion boards	b.g. Wall posts, forums	c.h. Online assessment forms, videos	d. Alerts, personal messages, status update	e.g.i. Resource sharing	f. Visual overview of care circle members	h. Video chat	j. Multiple formats		
Adverse Experience	a. Fewer decision Makers	b. Support and advice delay	c. Assessments participation is limited	d. Poor professionals-family communication	f. Feel demotivated to join and set up	g. Insufficient tech support				
Adverse Outcomes	a. Few care circle members frequently participate	b. May also increase risk	c. Lack of support by members of care circle	e. Perceived increase in work	f. Lack of motivation to join	g. Little, technical support for AT devices (partially tested)				

- a. Time and distance limitations prevent all members of care circle from participating in all meetings;
b. Only dedicated professionals can answer queries even when peers. Other care circle members might know the answer but need to wait. But, this is a major time and financial investment from professionals;
c. Assessment is usually only once a year;
d. Child may be unable to communicate problems between professionals and family members;
e. Multiple methods of communication are independently accessed, unstructured and uncoordinated;
f. Children are treated as one of many 'patients' or in isolation;
g. It is impossible for assessment centres to provide technical support on AT devices;
h. Therapy and help is offered onsite (location) only;
i. Need to search various websites and databases to find relevant information on schools and opportunities and still not have reliable answers;
j. Information pack is obtained only in hard copy.

Figure 9.5 - Worth Sketch Version 4

9.6. Summary of Iteration 6

The aims of this iteration were to continuously evaluate version 2 of the *artefact* and address any new requirements. The purpose of Activity 20 was to plan the evaluation. Activity 21 provided qualitative feedback on mycarecircle.co.uk from an independent user. Activity 22 recorded the demonstration and subsequent feedback from the Centre on continuous relevance of the research context and Activity 23 gathered feedback from three members of care circle who tried using the *artefact*.

9.7. Reflection on Iteration 6

This iteration focused on the *evaluation* of Version 2 of MCC, the *artefact*. It included four primary research activities.

9.7.1. Order of Activities 20-23

Activity 20 was planned and developed over the month of October 2012. Recruitment of participants started in November 2012 and closed in June 2013 when feedback from Activity 2013 was received. Findings from Activity 21 were received and Activity 22 was completed in April 2013. While feedback was continuously received, the intensity of work was low due to lack of response.

9.7.2. Scope of Iteration 6

Chapter 9 is similar to the stage recorded in Chapter 8 and focused on *evaluations* of *artefact* by *beneficiaries* against *purpose* (Figure 9.6).

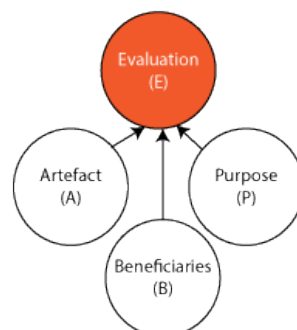


Figure 9.6 – Most Abstract Design Situation (MADS) of Chapter 9

Activities 20-23 were entirely focussed on *evaluation* and in practice were primarily evaluative. It was not possible derive a DAP list from Activity 20 as it was co-design and addition of content. Therefore, conceptual findings have been recorded for Activity 20. Activity 21 identified an additional *beneficiary* and Activity 23 identified additional *artefact* features. They confirmed the existing *purpose*, *beneficiaries* and *artefact* but also presented reasons as to why the *artefact* might not work. Therefore the need to recruit further participants and do further *evaluation* remained.

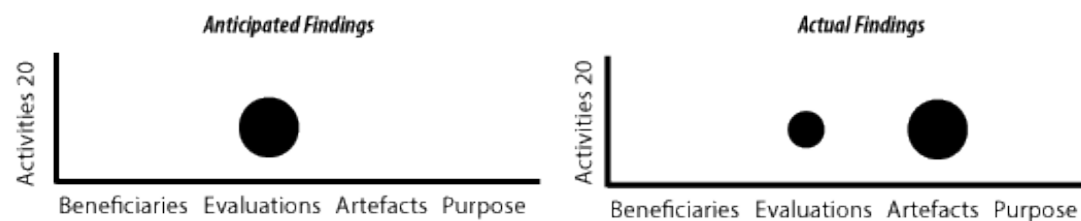


Figure 9.7 - Proportional Abstract Design Situation (PADS) of Activity 20– Co-Design and Evaluation Plan

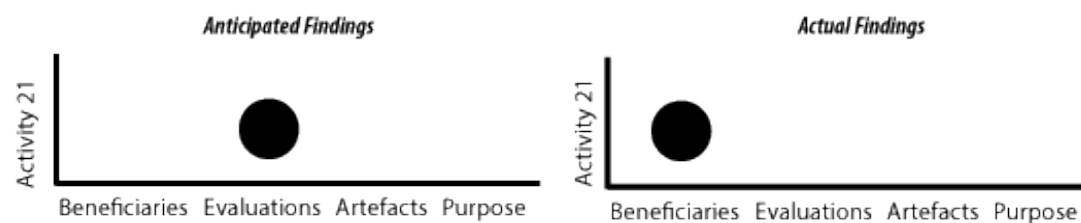


Figure 9.8 - Proportional Abstract Design Situation (PADS) of Activity 21 – Feedback from Independent user

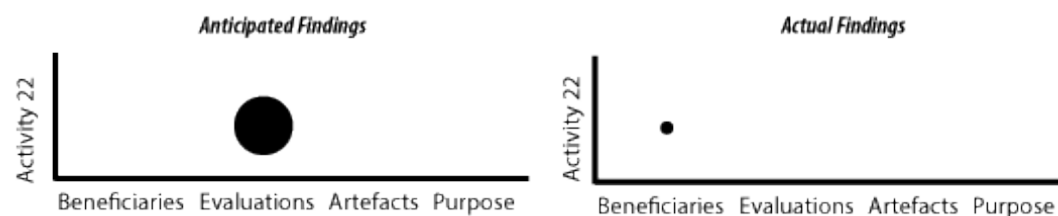


Figure 9.9 - Proportional Abstract Design Situation (PADS) of Activity 22 - Feedback from Assessment Centre

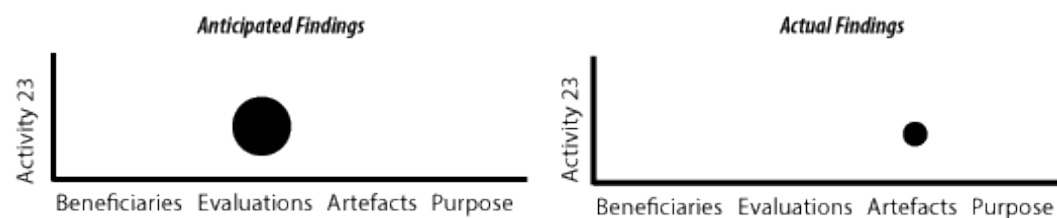


Figure 9.10 – Proportional Abstract Design Situation (PADS) of Activity 23 - Feedback from recruited care circle members

9.7.3. Progress in Iteration 6

The beginning of Chapter 6 (Introduction) discussed some potential research and design challenges based on the findings from Activities 1-8 that are likely to have affected the recruitment of participants. This section looks again at those concerns in light of the feedback produced by Activity 20 to 23 to see how it may have affected them.

Research challenges:

- *Would care circle members, especially the professionals, spend more time on disabled individual's needs? We cannot assume that they will do more than they would normally do;* While all participants confirmed the *artefact* would reduce the time taken to carry out their day-to-day activities, the initial task of setting up of the profiles for the user and the disabled individual take time. This may be a reason why some of the users did not get beyond signing up to the site.
- *The 'technical' involvement may be considered additional work for users not used to social networks, i.e., they need to devote effort to accessing and learning a new social network;* this was raised as a concern by both the independent evaluator and the Centre-based feedback. To add to this, sites of this nature may also be blocked from places such as the NHS, which may defeat the purpose of having medical practitioners being involved. However, if there was support from the NHS or a charity, MCC may be viable.
- *The artefact may find it difficult to accommodate different interaction requirements with different membership, environments and support needs for each care circle.* This was addressed by giving complete freedom to the legal guardian to recruit members and manage access settings. While there was initially an idea to visualise the care circle within MCC, this was abandoned as the membership, role and frequency of contact were different for each member in each circle.
- An additional challenge was in recruiting participants, particularly complete care circles. Securing funding to support professional marketing services may help in a more successful recruitment of participants. It is also uncertain if re-framing this design problem as a potential service design project may have also recruited more participants.

Design challenges:

- *Identifying the (de) motivations of care circle members and meeting their needs:* the direct recruits were comfortable using the platform. They reported difficulty in recruiting other members. To support this, an information leaflet was provided (by request from MCCM1 in Activity 22), which showed a service system focus.
- *If social networks are accessible to the user group:* The first version of the social network was fully accessible. The second version had reduced screen reader accessibility in order to accommodate some dynamic behaviour of the site, which was more user friendly. No users have reported as being affected by this yet.
- *Getting more members of the care circle involved and defining the extent to which they will be involved:* This remained an unresolved challenge.

Activity 20 planned the evaluation of this iteration and carried out co-design of MCC content. Table 9.1 in Activity 20 proposed several instruments for measuring worth as part of Step 5 in the evaluation plan. The worthwhile and adverse outcomes identified in Worth Sketch Version 3 were used in the tables to measure costs and benefits of the research. They were aligned to relevant resources that could be used as instruments of measurement. In addition, any worthwhile and/or adverse experiences that were not addressed in the worthwhile/adverse outcomes were also to be recorded. However, since substantial number of participants were not recruited, it was not possible measure these outcomes.

Activity 21 identified one further beneficiary and Activity 23 identified further design options.

The artefact and purpose it was built for was affirmed by the care circle members who engaged with MCC. However, the user recruitment was not successful and therefore the anticipated shift in design arenas did not occur except for in the case of some of the purposes (Table 9.4).

Table 9.4 –Shift of Design Arenas in Iteration 6

	<i>From</i>	<i>To</i>
<i>Beneficiaries</i>	Continuous and additional involvement of both professional and family members of the care circle	Continuous and additional involvement of both professional and personal roles.
<i>Evaluations</i>	Evaluated MCC, for usability, adequacy and desirability.	Some extended evaluation.
<i>Artefacts</i>	Evaluation and redesign of artefact.	Some affirmation of potential for artefact
<i>Purpose</i>	Purpose confirmed and extended by potential users.	Continuously meets identified and evolving purposes.

The evaluation was not collaborative but instead it included qualitative feedback from both professionals and family members, there was no independent usage of a complete care circle.

9.7.4. Resource Functions Analysis

The resources used in Activities 20-23 were generally the same as expected (Table 9.6).

Table 9.5 – Realities of Resource Functions in Iteration 6

Activity	Resource	Achieved Functions
Activity 20	Evaluation Planning & Co-operative Design	Directive, Protective, Performative
Activity 21	Independent usage	Informative, Inquisitive, Directive
Activity 22	Discussion	Informative, Inquisitive, Performative, Protective
Activity 23	Independent usage	Informative, Inquisitive
Cumulative Function		Informative, Invigorative

Performative demonstrations were carried out in Activities 20 and 22. All four Activities were *inquisitive*, and their findings *informative*. The lack of participant recruitment has also been *invigorative* of future considerations. Activity 20 was also *integrative* of several types of feedback from potential users.

9.7.5. Closing Personas Lifecycle

The three personas, Susan, Rachel and John need to be evaluated against their lifecycle (Pruitt & Adlin, 2005). Over Activities 1-8 and the results from the questionnaire, primary and secondary personas were built. This covered the Family Planning, Conception and

Gestation, and Birth and Maturation stages in the lifecycle of the personas. Once they were developed, they were used to write the usage scenarios from which requirements specifications were written and the interfaces were designed. They were mostly used for Cognitive Walkthrough. This covered the Adulthood stage of the personas. The reinforcement study and the subsequent feedback from users indicated the personas could be refined further but that the personas' purposes have largely been met. Even if refined further, it would not change the personas' characteristics and therefore the personas have now reached maturation (Pruitt & Adlin, 2005, p432-497) and can be preserved to co-develop the MCC in the future.

This iteration recorded continuous evaluation of MCC Version 2 and responses. While this was recorded as the sixth and final iteration of this research the continuous evaluation and development made each evaluation a separate iteration.

The next chapter reflects on the research process and analyses its findings.

Chapter 10 - Analysis of Research Approach and Case Study

This chapter presents reflections on the research process and presents its findings in a structure similar to the research approach in Chapter 2, at paradigm, methodology and resources levels. It then goes on to look at how it has extended the findings from Chapter 3 and contributed to the disability context.

10.1. Reflection on Tracking

As part of this research, details of activity, duration and whether activities were parallel or sequential were tracked. Part of the tracking is shown in Figure 10.1 and complete tracking is provided in Appendix C10 – Tracking in full. This section makes observations on anticipations vs. reality of duration of activities and iterations; how the various components of the thesis work together; how problem and solution spaces evolved; how reflection *on* action was carried out and establishes the importance of reflection *in* an RtD process.

	Dec-08	Jan-09	Feb-09	Mar-09	Apr-09	May-09	Jun-09	Jul-09
General	Beyond Bodies; Socio technical systems;						Slight amendments to RQs;	
C1: Introduction								
C2: Contextual Review								ICF model in detail for choice
C3: Research Approach				MPs expanded;				Participatory Design;
C4: Activities 1-4		Activity 4: Reflection on Personal Experience and Activity 5: STS started		Worth Map introduced; Locales;	Explored alternative models (sequential, flow, etc.)			
C5: Activities 5-8	Proposal to ACE on Speech Bubble					End of Activity 5: New Socio-tech		Worth Web 1; Activity 7: 21st July 2009 Ace Centre Interviews
C6 - Activities 9-11							Questionnaires Design Started	

Figure 10.1 - Sample of Tracking (Dec 08-Jul 09)

The entire research spanned a period of eighty months part-time activity. This included approximately eight months of preparatory research prior to the commencement of the PhD, a break of approximately six months that occurred when transferring Universities, and several further breaks due to work related international travels approximately every other week over 2012-2014 making it a total duration of 48 weeks part-time until the write up. The sequence and duration of the individual activities were explained in the reflection section at the end of

iterations. The tracking shows that research and activities were carried out as and when the opportunity arose. This was significant because it meant that the research and activities were neither planned to be sequential, nor carried out sequentially; instead analyses were retrospectively incorporated into each iteration based on their relevance. For example, meta-principles and design arenas did not exist until 2009; ADS until mid 2010 and resource functions until 2013. They were incorporated as and when they were published. This is in contrast to the more idealised engineering design model where designers follow a series of sequential iterations of steps. This retrospective analysis is also an accepted, but not well understood, approach by the RtD community. This research uses it to reveal the iterative nature of a design process.

The activities recorded in Chapter 4 (Iteration 1) took place over a year and Chapter 5 (Iteration 2) over 6 months, but had to be revisited several times for reflection, and implementation of different (potential) worth focused resources.

Chapter 6 (Iteration 3) took 18 months to complete. This iteration saw the development of a unique *balanced* approach to questionnaire design that *integrated* worth focused resources, as shown for Activities 9-11 (Chapter 6, Iteration 3). While in retrospect it was not surprising, the design of the questionnaire took longer than the pilot, fielding and evaluation.

Chapters 7-9 (Iterations 4-6) over 2011-2012 focused on the development and evaluation. This was also the time my work commitments required constant overseas travels and may have impeded more substantial progress in recruitment of participants. An observation in Chapter 9 (Iteration 6) is where further development takes place following three sets of evaluations and three discrete cycles are embedded within.

This process has also been a demonstration of what Schön (1983) describes as double loop learning where the research started with an idea of the social setting and the first loop was making strategic moves to get to the design solution and the second loop was reflectively evaluating the role of reflection and research approached.

All reflection sections at the end of the iterations have the following structure:

- Order of activities: a table showing the chronology of events;

- Scope of iteration: A presentation of progressive Abstract Design Situation (ADS) in the form of Most Abstract Design Situations (MADs) and Proportional Abstract Design Situation (PADs)
- Progress of Iteration: Shift of Design Arenas and discussion;
- Resource Functions Analysis (RFA): A RFA is carried out and achieved functions for each of the activities from within the iteration are presented.

Based on the tracked order of activities, a general observation was that with each iteration, the duration of the evaluation activity cycle became shorter and the last Activity (23, Chapter 9, Iteration 6) was comprised of three small cycles where developments occurred after each feedback. This could be due to the research approach having stabilised but primarily as identification of new contributions to the design context reduced.

The tracking also shows that not all the activities contributed to the on-going design process. For example, in Chapter 4 (Iteration 1), activities such as building of locales and mobility maps were developed. These established a focus on communications between care circle members, however the diagrams themselves no longer contributed to the next phases of research and were therefore discarded and are not included within the thesis.

Another example was when an initial version of Contextual Review (Chapter 3) contained a detailed study on existing AT. It was based on a biomedical approach to disability and was inadequate. It was one particular instance where work done as part of this RtD did not contribute directly to the eventual design solution. This was however a significant step since it meant the research had to focus on a holistic approach as described by ICF and not the more common biomedical approach. It showed that a designer must be prepared to find that existing design research is not always helpful, particularly if that research is predicated on outmoded concepts particular to the design setting. This illustrated the organic nature of the design process in practice and that the designers' perspective may shift as new findings or insights emerge (Dorst and Cross, 2001).

As can be seen from the tracking (Appendix C10), I reviewed and changed the research approach throughout the PhD candidature. When the initial research problem was committed to, the aim was to use worth-centred development to reach an appropriate web-based solution. It started with the ICF model as a design approach then acknowledge engineering as the approach that shifted to the iterative Microsoft Research Design Cycle approach that was

finally replaced by a more open approach to RtD that was parallel; had reflective stops and Total Iteration Potential. Over the duration of this PhD, the underpinning research principles changed as the focus of the PhD, which had started in computing, shifted to design.

In science and engineering disciplines, a research process requires that a research question and subsequent methodology be determined at the start of the research. However, the tracking shows that practice-based research continuously evolves both problem and solutions spaces (Dorst and Cross, 2001) and therefore the problem is continuously reframed by regular reflection on design purpose and beneficiaries' contexts. The solution can also be seen in the shift in the envisaged artefact from a form of Decision Support System (DSS) to a social support system. This is further evidenced by the tracking of Iteration Shifts and Anticipated Iteration Shifts.

While Chapter 2 (Research Paradigms, Methodologies and Methods) ends with the approach to be taken as RtD with reflection and naturalistic approaches as this PhD thesis' paradigm, parallel methodology for process and several resources for methods, the research approach shifted throughout the PhD. Contrary to preferred scientific practice, the research approach was not planned for the entire process. Reflective spaces were provided to reconsider relevant practices and literatures and when appropriate change the research approach itself. These included emergent stops at the end of activities and additional space for Resource Function Analysis (RFA). One significant change to methodology was throughout 2008-2011 the focus was on Microsoft Research (MSR) design cycle, which was used to structure the research into discrete phases according to the MSR design cycle steps. It is evident from the tracking (Appendix C10), that it was indeed possible to start the next iteration before the previous iteration ended. For example, Iteration 3 (Chapter 6) started with questionnaire design ideas before previous Iteration 2 was fully concluded. This was an early indicator of the need to drop the MSR Cycle and any commitment to wholly sequential activities. Therefore, this methodology was discarded and replaced by a more open paradigm and related methodology when it was identified as an inappropriate idealised engineering design model.

Similarly, meta-principles combined with Abstract Design Situations (ADS) were used to evaluate the activities making up the research from 2009. Emergent stops were also made where the resources were planned and evaluated at the end of each chapter. This started with an attempt to use the meta-principles vocabulary to identify which principles were met in

each of the activities. This did support evaluation of resources (out of the box), but was not specific to resources used/completed resource. Meta-principles would not have been realised without resource functions. The Framework combines meta-principles for design, ADS and resource functions and therefore, towards the end of 2014, meta-principles were replaced by resource functions as a reflective construct. This shows that in RtD the reflective approach can continuously evolve.

The findings from activities were grouped into design arenas in 2009. However, with further reflection and analysis of the activity records, they were edited and moved to other design arenas, several times, with the final changes being in 2015 during write-up of the thesis. These findings were called Design Arena Progress (DAP) lists. In hindsight, this showed that some findings may not fit into a single design arena. They could either belong in more than one design arenas or connect them together. These findings were connected using the Worth Integration Tables in Iterations 1 and 2. However, if some findings had originally been identified to be connections, creation of these tables would have been significantly easier. The numbers assigned to these findings were retrospectively added to link them to the table. This meant that even if any misalignments existed in the DAP lists, they would be addressed by the connections in the Worth Integration Tables within the same Iteration and could therefore be ignored.

This design research process was *Balanced, Integrated and Generous* (BIG). While the research started with the aim of producing an *artefact*, the focus of the research continuously shifted. Understanding *purpose, beneficiaries* and *artefact* was followed by *evaluation* which was followed by design of *artefact* and thereafter a return to *evaluation*. Each iteration showed the shift in focus and also how the various design arenas were connected. Thus it was a *balanced* design. Several resources such as Worth Integration Table, Artefact Connection Table, Worth Focused Personas were used to *integrate* the findings from research activities. These resources *integrated* between and within design arenas. As RtD, the research process was *generous* in the choice of resources it used.

Having reflected on the reflection process of documenting the thesis, the next Section 10.2 analyses the various aspects of the research approach and the MCC case study.

10.2. Research *into*, *for* and *through* Design

Chapter 2 arrived at the chosen research paradigm as Action Research using Research through Design (RtD) with naturalistic approaches within human contexts. RtD was studied with a focus on Frayling (1994)'s identification of different modes of research *into*, *for* and *through* design using historic anecdotes of practices in art and design. The following section presents evidence of how these modes of research often not mutually exclusive (Yee, 2010): are design research often moves in and out of these modes. The various activities in the study are used to expand on the understanding and interpretation of Frayling's terms.

10.2.1. Research *into* Design

Frayling refers to research *into* design as the most straightforward form of research usually being historical research, aesthetical or perceptual research with a variety of theoretical perspectives on art and design. As with Research *for*, Research *into* is only research when it meets the Frascati definition, so only significant contributions that result from reflection *on* action count as Research *into* design.

It is (small r) research *into* design whenever something new and significant is identified from the design work that is being carried out. It is also *into* when contributions to understanding of design research practices are made. This could also be in the form of final theses.

In this PhD case study, (small r) research *into* design examined the existing corpus of evidence about design and designing by using secondary research and also produced a corpus of data. This included literature on design models, design theory and practice and achievements (Chapter 2). Each iteration produced a corpus of data, based on which the next iteration was planned, which in effect created the methodology. While research theories had to be explored in Chapter 2 to understand the research approach, this RtD process evidenced that theory can be guided by practice. This also confirmed Gaver (2012)'s view that practical knowledge can lead to substantive knowledge. This is evident from further research *into* design in Activity 5 (Chapter 5) where STSs were explored and again in Chapter 10 and 11 in which it was necessary to revert to literature to verify the findings.

Research *into* design mostly used had my own corpus of design work as a focus for reflection. Thus, the meta-analysis of the research *into* design provided information relevant to research *for* design.

10.2.2. Research *for* Design

Frayling refers to Research *for* design as the ‘thorny one’ amongst the three modes. He further analyses it as the thinking or research element being embodied within the artefact. In his example, Frayling refers to artistic references that Picasso gathers to inspire his painting (as research with a small r for design) but does not provide any information on what may count as (big R) Research *for* design. He also refers to Picasso’s reference as the spirit of research but not the objective that would make it Research *for* design. This research takes the view that original reusable design resources produced by this research is Research *for* design.

Research (small r) *for* design in this PhD was the contextual review where disability models, existing models for choice and use of AT, assessment approaches, AT devices and existing legislation and guidance (Chapter 3) and Activity 8 in CAT models where potential social networks were referred to. It was also research *for* design when potential STSs that partially met these needs were explored (Activities 5) and were expanded once it was established that the design artefact needed to go beyond the parameters of STSs. In this research, the process of determining whether a suitable design solution for the situation at hand existed was research *for* design, i.e, routine activities in support of RtD.

More generally, research to aid the design should be communicable or re-usable knowledge, declarative, procedural or some mix of resource functions. Thus Frayling’s description of research *for* design needs to be extended further. In the case of this PhD, it was also research (small r) *for* design whenever activities were carried out to understand design needs and effectiveness, producing new worth-focused resources for design (Chapters 4-6, and 8-9) for examples, personas, questionnaire design process and worth connection, tables. It was also Research (big R) *for* Design when contributions to design research methodology and future practice were made via these resources.

10.2.3. Research *through* Design

The RtD process included several design activities. This also supports Zimmerman and Forlizzi (2011, p.15)’s view that RtD is “a research approach that follows a design process of

making things (design inquiry) where the goal is the production of knowledge, not a commercially successful product”.

In this PhD case study, RtD was the mode of research each time a design move was made. This occurred during the entire research process encompassing research *for* and *into* design guided by reflection *on* action. This started with the understanding of the design situation in Chapter 2, developing the understanding through several research *for* design activities, and research *into* design data where Versions 1 and 2 of My Care Circle (MCC) were produced.

Further, Version 2 of MCC as an artefact on its own would not be a research contribution. As a curated artefact within the RtD process, which records cumulative findings from each of the preceding activities, the artefact signifies the relationships between the design choices and making it a significant research contribution. This is evidenced by the tracking of Design Arena Progress (DAP) lists at the end of each activity and the cumulative summary at the end of each iteration that were used to specify the requirements.

The entire research process, recorded in detail, provided an opportunity for continuous reflection, is research *through* design. Chapters 2 and 3 are a mix of research *for* design, the former focusing on declarative (informative) knowledge and the latter methodological. Chapters 4 onwards, it is research *for* when primary or secondary research is carried out and *into* (secondary) when the research only contributes to design moves at reflection. It is Research *for* Design (big D) when original methodological contributions are made in the form of resources, which is an output of knowledge via the RtD process.

10.3. Reflection *in* and *on* Action

A key aim of this thesis was to look at how Research *through*, *into* and *for* Design work in support of each mode. In addition, Reflection *in* and *on* Action was also mapped against this, as Reflection *on* Design was the same as Research *into* Design.

Research *through* design is a research enquiry process, covering the entire design process except for when stops are made to carry out Research *into* design.

Significant contributions that result from Reflection *on* Action count as resulting from Research *into* design when making a stop to analyse the corpus of information produced through RtD. This reflection happened at the end of Chapters 2-9, each of which marked the

end of one or more research activities. In addition, this chapter is dedicated to reflect on the entire RtD process.

Research *for* design (frascati definition) is when original reusable design resources are produced by this research. Reflection *on* action may also happen during research *for* design.

Reflection *in* Action occurred within Research *through* Design when an immediate action had to be taken to respond to any new opportunities that arose.

Figure 10.1 shows the structure of this thesis mapped against these components. The vertical axis shows Research *through* and *for* design against horizontal axis based on chapters.

Research *in* Design and Reflection *on* Action are marked on this timeline. Any Reflection *in* Action is marked using circles. The dots refer to activities where reflection *in* action happened. The straight lines show Research *through* and *for* design.

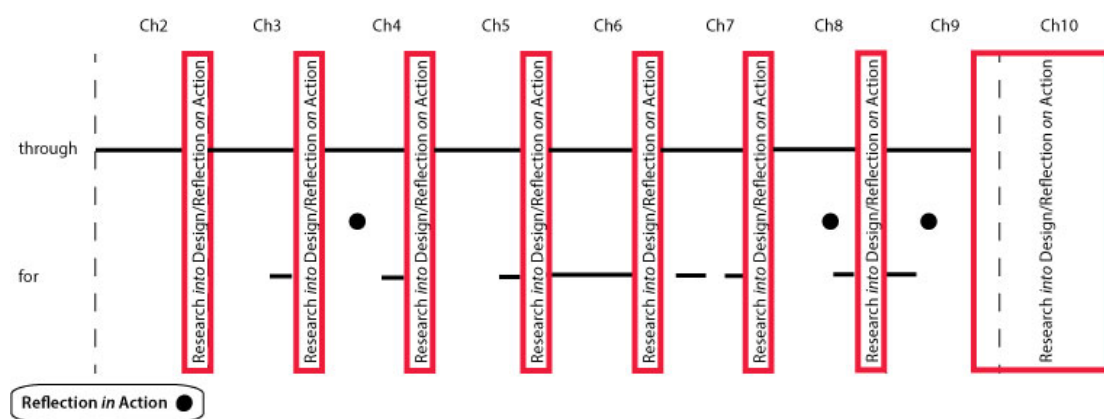


Figure 10.2 – Research through, into and for Design and Reflection in and on Action Process.

When considering the reflection process, (look, think and act), planning also becomes significant. Much of the research *through* and *for* design activities were planned, and resulted from reflection *on* action.

One example on reflection *on* action *into* design is while Chapters 2 and 3 covered literature, reflection (*on*) at the end of Iteration 1 required a return to reviewing literature with regard to STSs. The reflections *in* action showed that at times the planned iteration too had to change due to opportunities that arose (eg. Activity 3). While the iterations were closed after the sixth iteration (Chapter 9), there is a return in this chapter to reflect *on* the action taken to reach conclusions.

Without reflection, it is also not possible to identify knowledge produced by the RtD process or recognise design moves. For example, the reflection shifted the design from a Decision Support System to a Socio-Technical System and again to an informative and collaborative Social Support System. Another example being the *purpose, artefact and beneficiaries* enabled provided the basis for the idea, confirmed the concept and supported the materialization.

RtD process must be led by reflection *on* action, which will in turn direct the research. If there is to be an overall reflection on the process (such as this chapter), then the entire process needs to be systematically tracked. There is not much evidence for reflection *in* action in the earlier chapters of this RtD process primarily because RtD and reflection were retrospectively introduced to the process and perhaps the RtD process itself reduces the need for reflection *in* action. Thus, the different forms of research in design diverge, converge and shift at different points of the research process with continuous reflection.

10.3.1. Total Iteration Potential

Chapter 2 selected a parallel methodology where activities can be carried out at the same time and design arenas are iterated within and across activities. This was reflected in the realities of the research (shown in part of the tracking in Figure 10.1 and Appendix C10 – Tracking in full) where multiple activities were happening concurrently.

Total iterations are also possible only in parallel methodologies. In 2005, Cockton proposed Total Iteration Potential (TIP) as allowing iteration at any stage, but only having a single focus on one stage at any one time, which could also be sequential. Iteration may apply to both the design process and to the design itself where activities may have to be repeated by going one or more steps back and then moving forward again, which showed two levels of TIP. Iteration also meant the focus of activities could shift between design arenas where the focus of an activity may, for example, be on identifying further *beneficiaries*, *evaluating* an artefact, designing the *artefact* or understanding the design *purpose* while potentially also adding to coordinating with the remaining design arenas. Reflection *on* action was necessary for these moves and this also showed that TIP could not be fully total in a sequential methodology.

The way the activities have been grouped into iterations in this thesis show that there is no fixed pre-defined process structure, beyond stage' start and end at reflective points where it is possible to take stock and start the next iteration, (*progressive instantiation*). Each reflective point committed to identified *beneficiaries*, *artefact* features and *purpose* and informed the progress of the design process by framing the problem and moving towards a solution. Each stage advances one or more design arenas in varying degrees, which is a very different approach to Cockton's (2005) proposal where phases of design are associated with specific design arenas. So once again, this research significantly revises Cockton's (2005) Value-Centred Design (VCD) to take account of the realities of ADSs.

As mentioned in Chapter 2, Cockton (2009) provided a useful description of the reflection point via progressive instantiation. He illustrated this by adopting a worth-focused approach where meta-principles were used for reflection and refined as rules for progressive instantiation. However, there has been no follow up since. This research evidences progressive instantiation adopting a worth-focused approach similar to Cockton (2009) but with resource functions instead of meta-principles.

10.3.2. Abstract Design Situation (ADS)

An overview of design arenas (*beneficiaries*, *evaluations*, *artefact* and *purpose*), their connections, and the primary generator (as tracked) can be found in Figure 10.2. It shows how design arenas were iterated and connected throughout the research. The dotted circles show design arenas where no progress has been made; the black outlined circles where there have been design moves; orange circles are the resulting primary foci of each activity or iteration and the arrows show how the design arenas connect. Thus, the process changed focus and co-ordination based on the findings for in each iteration.

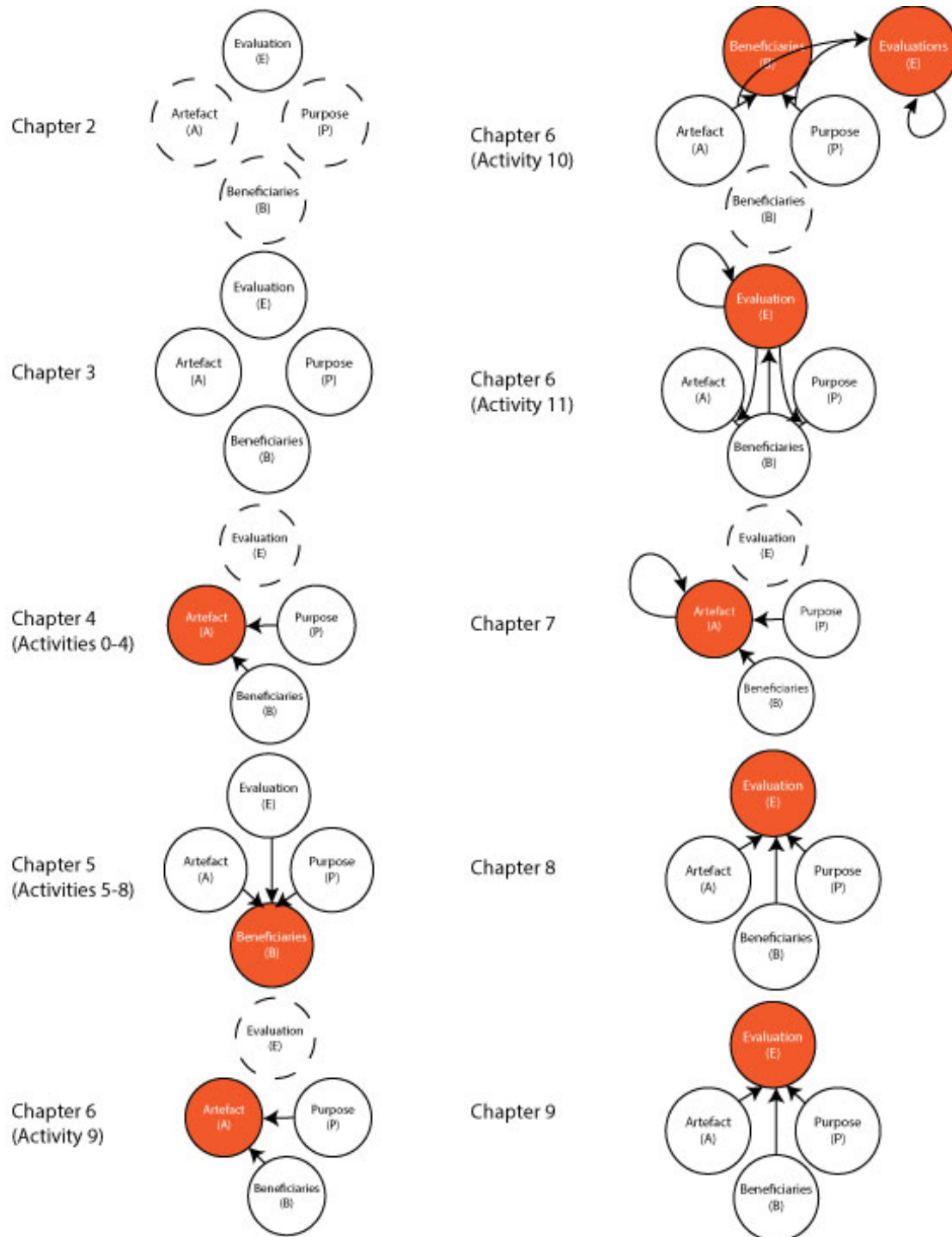


Figure 10.3 - Design Arenas, their connections and the primary generator

Iterations are reflection *on* action and improve the co-ordination of *beneficiaries*, *evaluations* and *artefact* with *purpose*. This worth-focused approach contributes to the co-evolution of problem and solution spaces and hopefully increases the understanding of design context beyond the preceding one. Chapter 2 set out the understanding of the design context by secondary research. Chapters 4-5 carried out primary activities and significantly increased the

understanding of *beneficiaries*, *artefact* and *purpose*. Chapter 6 confirmed this understanding and found some additional information. The design and development took place as recorded in Chapter 7. Continuous evaluation was conducted in Chapters 8 and 9 where additional information about *beneficiaries*, *artefact* and *purpose* were identified but it was significantly less than Chapters 4-6. Thus, the understanding of the design problem improved after the development of the *artefact*, but it was less so than the shift before development. This also showed that continuous involvement of the users would continue to refine the problem and solution spaces.

Figure 10.2 also shows that the design arena in focus starts with *evaluations* in Chapter 2 but subsequently, in Chapter 3, other design arenas are added but without connections, and then connections get added from Chapter 4. Chapter 3 also focuses on possible *purpose* elements and understanding design arenas with a focus on each one of them. It is at the end of the activities in Chapter 4 and 5 where the RtD becomes concretely worth-focused, and the first worth sketch is produced. An additional observation is Activity 11 where the *artefact-beneficiary* and *purpose-beneficiary* connections are evaluated. This is followed by *evaluation-evaluation* (loop, Chapter 6) and *artefact-artefact* (Chapter 7) loops. This showed that the iterations became increasingly complex.

In retrospect, the recording of ADS enabled the recognition of the shift in foci with each activity and iteration. This led to the necessity of different levels of an abstraction rather than ADS as described by Cockton (2013a). The most abstract form of ADS is where design arenas and its connections are looked at without any content to recognise whether a design arenas was added, removed or any connections changed. This was recognised and named Most Abstract Design Situation (MADS) in this thesis.

One original identification due to MADS was the identification of *evaluation of evaluation* in Chapter 6 when the questionnaire was piloted and again in Chapter 9 when the *evaluation* process was *evaluated*. This extends Cockton's (2006) concept of TIP and demonstration of *evaluation* to a loop in the design context as can be identified in Figure 10.2. This loop also applies to *artefact*, where designing individual components of the design process (*artefact*), eg. wireframes, that lead to the design and development of the *artefact*.

Each iteration also provided a snapshot that showed the anticipated/planned and actual *balance* of design arenas. Figure 10.3 shows how much proportional findings were made for

each of the design arenas in each activity or group of activities. This demonstrated the expected and actual *balance* of design arenas within each activity. In addition, it also showed that while there is an anticipation of design moves (left side of the figure), design moves cannot be planned and are likely to be different (right side of the figure). It was not always possible to measure the actual findings, especially integrative activities such as Personas and Questionnaire design. In this case, actual findings were recorded at a conceptual level. Figure 10.3 shows these conceptual findings in grey (right side of the figure). This is the second level of abstraction and a progression from MADS and is an original contribution to an ADS level and is called Proportional Abstract Design Situation (PADS).

During reflection *on* action at the end of each iteration, an overview of findings were recorded under each design arena to take a snapshot of the progress made. This assigns magnitudes to the detail in the form of a Design Arena Progress (DAP) list. This was the next level of abstraction and the most concrete.

When these findings from the DAP lists are compared against what was achieved in the previous iteration, it provides a snapshot of the shift in design problem and/or solution space. This is presented throughout the thesis by a from-to table and is called Iteration Shift. Further, these Iteration Shift tables are also used to record anticipated shifts for the following Iteration. This original concept from this PhD was introduced as ‘Reflection Points’ at Northumbria University by Cockton in 2015 over a few lectures.

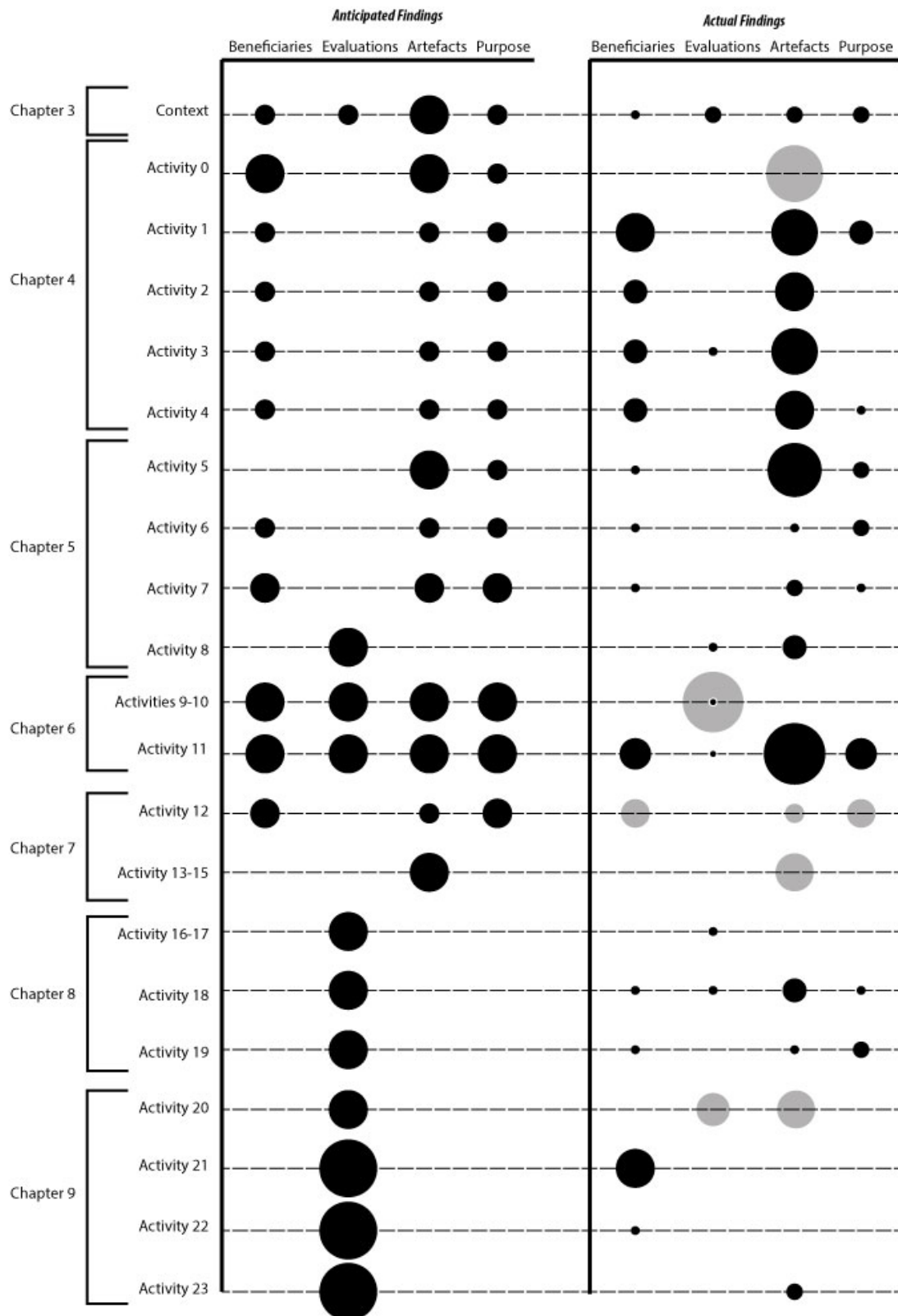


Figure 10.3– Balance and Realities of Design Arena Overviews

Thus, three new levels of abstraction was introduced for an ADS. Most Abstract Design Situations (MADS) showed the design arenas in focus (primary generator), whether design

arenas or its co-ordinations were added, remained unchanged or shifted for an activity. Proportional Abstract Design Situation (PADS) were introduced to compare the difference in anticipated and actual proportional findings. Iteration shift outlined the shift in design progress for iterations.

10.3.3. Primary Generator

The methodology also stated that a *balanced* approach is more important than one that is focused on a single design arena, contrary to Darke (1979)'s concept of a *primary generator*, that was seen as a *conjecture* within a process of *generator-conjecture-analysis* where the *artefact* concept or objective that generates a solution is called the *primary generator*.

In each iteration, the design arena in focus was retrospectively identified, which challenges Darke (1979)'s claim that the primary generator, in her case the *artefact*, leads the design. Each iteration was driven by data that is obtained from focusing on users and research *for* design, validation of findings and refinement. This is similar to what Darke describes as *conjecture*. It is possible to say that *conjecture* leads the design but can only be established as a *primary generator* in retrospect.

The primary focus started with *artefact* and moved to *beneficiaries*, returned to *artefact*, again to *beneficiaries* and then *evaluation*. This is different to Darke (1979) where, the *primary generator (artefact)* leads the entire design process. Overall, the design aim was indeed to create an *artefact* that would meet the needs of the *beneficiaries* and their *purposes*. This meant that the overarching focus was on the *artefact*, which according to Darke would have been a single *conjecture* or *primary generator*, but there was a more complex set of shifting foci throughout the process.

This research therefore challenges Darke's (1979) position that a single *primary generator* leads the design process, and has shown that the concept of *primary generator* within the design context more than thirty-five years later is more complex. Darke's theory is therefore refuted stating *conjectures* to be leading and *generators* recognised retrospectively within design. There are different generators coordinating with other design arenas at different points of the RtD and may also be different to what was anticipated and therefore there cannot be a single *primary generator* leading the design. Instead, *conjecture* is the concept that leads the process.

10.3.4. Resource Functions

The reflections were originally partially structured using Cockton's Meta-Principles to create a snapshot of activities. In 2012, Cockton introduced the resource functions in his Working to Choose (W2C) Framework where he showed that meta-principles assess realisations of potential resource functions. Therefore, the reflections at the end of iterations were revised to use *resource functions* vocabulary instead of meta-principles. In the context of this PhD, resource functions vocabulary was used for the evaluation of each resource used and then again at the end of each iteration.

The anticipated functions of planned approach or resource were recorded in Chapter 2 as primary, potential and unlikely functions. Chapter 2 (Section 2.9) summarised the anticipated resource functions and a summary of actual resource functions from end of Iterations 1-6 can be found in Table 10.1.

Table 10.1 - Summary of Resource Functions

Activity	Resource/Approach	Achieved Functions
Activity 0	DSS knowledge	Adumbrative
Activity 1	Interviews	Inquisitive, Informative, Invigorative
Activity 2	Participant Observation	Inquisitive, Informative, Invigorative
Activity 3	Interviews	Inquisitive, Directive, Informative, Invigorative
Activity 4	Autobiographical reflection	Directive, Informative
Cumulative Functions		Adumbrative, Invigorative, Expressive, Integrative
Activity 5	Desk/Secondary research	Ameliorative, Informative
Activity 6	Discussion	Informative, Inquisitive, Invigorative, Protective
Activity 7	Interviews	Expressive, Informative, Inquisitive, Invigorative, Performative, Protective
Activity 8	CAT model	Expressive, Informative, Inquisitive, Invigorative, Protective
Cumulative Functions		Invigorative
Activity 9	Questionnaire Design	Expressive, Protective
Activity 10	Questionnaire Pilot	Expressive, Informative, Inquisitive, Protective
Activity 11	Questionnaire Fielding	Expressive, Informative, Inquisitive, Protective

Activity	Resource/Approach	Achieved Functions
Cumulative Functions		Informative, Expressive
Activity 12	Personas	Expressive, Integrative, Protective
Activity 13	Requirement Specification	Expressive, Protective
Activity 14	Co-operative design	Inquisitive, Expressive, Informative
Activity 14	Wireframes	Expressive, Protective
Activity 15	Development	Integrative, Expressive
Cumulative Functions		Expressive
Activity 16	Cognitive Walkthrough	Inquisitive, Informative, Protective
Activity 17	Heuristic Evaluation	Inquisitive, Expressive, Informative, Protective
Activity 18	Usability testing	Inquisitive, Informative, Performative, Expressive
Activity 19	Interviews	Inquisitive, Informative, Invigorative, Performative
Activity 19	Participant Observation	Inquisitive, Informative
Cumulative Functions		Protective
Activity 20	Evaluation Planning & Co-operative Design	Directive, Protective
Activity 21	Independent usage	Informative, Inquisitive
Activity 22	Discussion	Informative, Inquisitive, Performative, Protective
Cumulative Functions		Informative

Most of this thesis, particularly Chapter 4 onwards, documented the approaches used in the process and reflected on the realised functions of the resources compared to what was anticipated. Thus resource functions were identified retrospectively to analyse individual activities and iterations, compare against the anticipated functions, and were used as a basis for reflection *on action*.

In addition to what Cockton (2013a) proposed, resource functions were also used to reflect on the iteration as a whole to recognise the shift made by the iteration and were called *cumulative functions*, which is an original contribution to W2C. A cumulative function is the overall retrospective function of iterations, without individually looking at the activities. They expose ephemeral functions of shorter activities or tasks within activities, e.g. Demonstration prior to interview. Cumulative functions also take the position that the function of the iteration is greater than the sum of its parts (activities). This is significant as it also provided vocabulary for reflecting on the groups of activities for an iteration.

The resource function with the highest use is *informative* (18), followed by *inquisitive* (15), *protective* (12), *expressive* (11), *invigorative* (7), *performative* (4), *directive* (3), *integrative* (2) with the least use for *ameliorative* (1) and *adumbrative* (1) (Table 10.1).

All *inquisitive* resources became *informative*. In addition, *inquisitive* resources could also be *directive* (guiding design work) or *invigorative* (triggering further activities). It is not surprising that *informative* was the most frequent function since most activities focused on being *inquisitive* and obtaining primary or secondary information, which evidences a User-Centred Design process. The process also *integrated* information acquired by *inquisitive* and often careful (*protective*) activities. These activities included demonstrated designs (*expressive*) that led the development (*directive*) of the design artefact. Some activities also included *demonstrations* of the artefact usage. Personas were however *expressive* resources that were used as a *directive* resource later. However, it was also noticeable that all resources that were discarded were *expressive* resources that could not be used for anything else.

10.4. Annotation and Resources

The research activities consisted of resources with some of them annotated. This Section (10.4) discussed the annotated resources, resources used, and their functions.

10.4.1. Annotations

Research on creative design processes often uses workbooks, annotated artefacts and portfolios (Gaver, 2012; Bowers, 2012; Löwgren, 2013). Both Gaver and Bowers describe annotated portfolios as intermediate level knowledge that is more detailed than abstract theory, which communicate design research and deal more closely with design requirements. These are the evidence for the knowledge that is created as part of reflection *on* action that relate design moves to secondary literature within a RtD paradigm.

Activity 12 shows how the personas are annotated with comments on how the details are derived. These annotated personas were used to integrate findings, plan usage scenarios and move the process forward, subsequently contributing to the artefact development. This extended Gaver and Bower (2012)'s description of annotation by extending it beyond artefact to integrating *beneficiaries*, *purpose* and *artefacts*. Annotations were also done as part of the design process on user research such as questionnaire design and worth related artefacts

worth sketches, worth tables and element measurement tables, which made resources reusable. Thus, annotations were done at both iteration level and resource level. It is also worth noting that the annotations were carried out in parallel for the activities taking place, refined and brought together with further annotations at reflective points.

10.4.2. Resources

At the beginning of the RtD process, an initial understanding of the design problem was identified based on secondary research. With each activity and iteration, design arenas were recorded to identify design moves that were incrementally made. This thesis fully documents this worth-focused process (shown in Figure 10.4) that evolved during the development of a Socio-Technical System. It shows how the process encompassed several worth-focused resources including established activities and new ones.

The green boxes in Figure 10.4 show the activities while the purple boxes show reflections, including the resources used for them. Participants were continuously involved providing information on *beneficiaries*, *artefacts* and *purpose*. This continuous worth-focused work with participants, described in Chapters 4, 5, 6, 8 and 9, established that worth-focused methods were indeed worthwhile, with respect to a wide range of evaluation criteria such as design choices, worth sketches and resource functions. The evaluation of RtD is based on a challenging realistic design context throughout the research, reflecting on their effectiveness, efficiency and stability, alongside other evaluation criteria.

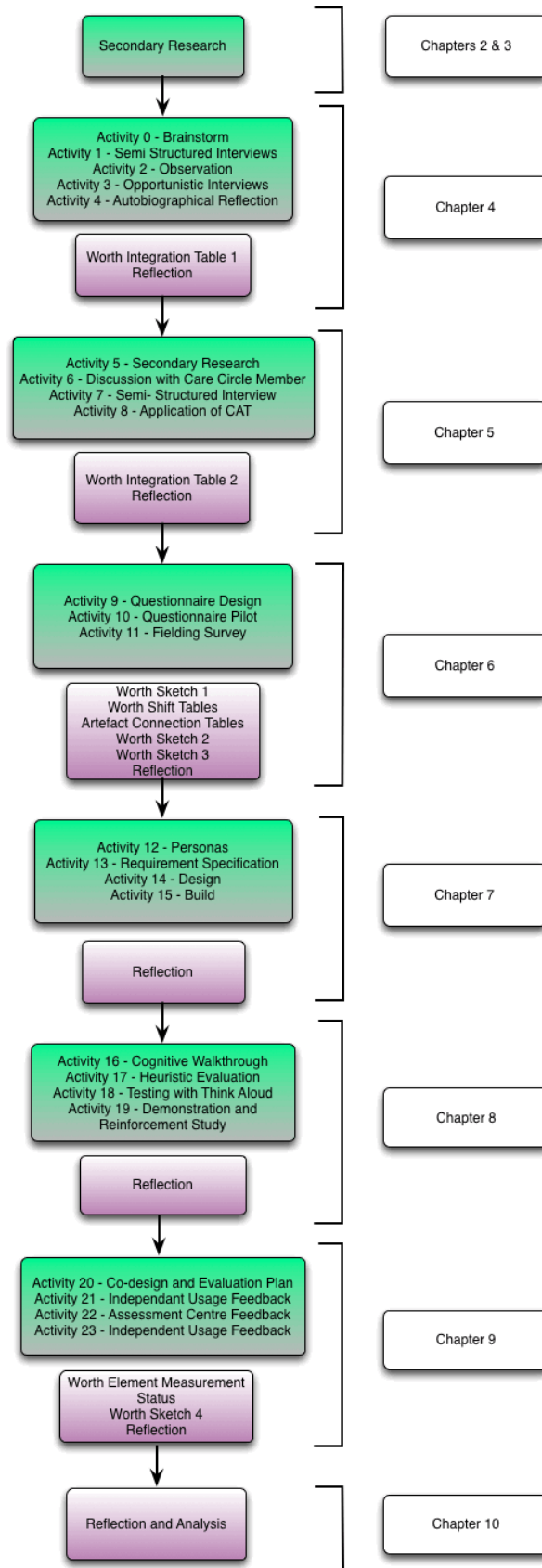


Figure 10.4 - Worth Focused Activities

This worth-focused design approach within the RtD process, which once fully realised in design practice, manifests itself via design and evaluation resources that will be available for reuse or adaptation in the future. Detailed notes of all activities were kept, and were organised and utilised retrospectively in this thesis. This helped effective reflection and identification of reused, adapted and original resources.

New worth-focused resources developed in the case study include novel worth integration tables (Chapters 4 and 5), worth shift tables (Chapter 6), a worth-focused and coordinated approach to questionnaire design (Chapter 6), worth focused personas (Chapter 7) and further development on the worth focused evaluation process that was proposed by Cockton (2005) and far more extensive than Camara, *et al.*, (2013), (Chapters 8 and 9).

The use of Personas was inspired by Olsen's (2004) structure and Pruitt and Adlin's (2006) lifecycle but restructured and simplified for this research. Except for creative narrative additions, most statements in the personas were annotated against findings from preceding activities that had been carried out. These personas were annotated with rationale for all key statements that were included, which made the Personas a unique worth-focused integrative resource.

Worth shift tables (Chapter 6) were a novel idea that presented both the current and ideal situations and tables that included a mapping of *purpose* and *beneficiaries* with *artefacts*. This demonstrated Zimmerman *et.al*, (2007)'s design for the world that shifts design situations from current to ideal situations. The worth shift tables led to separating missing information and information that required confirmation, and as a result supported yet another unique process, worth focused questionnaire design. Each question was mapped against the data on this table to justify inclusion.

Artefact connection tables were introduced to map artefact features against increased benefits and reduced costs/aversion/lack. This is similar to the feature-benefit table used by Grikscheit and his team (1993) and was the first time a business model was used in an RtD process.

The worth focused evaluation of the artefact was unique in planning how each criterion was to be evaluated. A resource used for this purpose was worth element measurement tables, that were used to plan evaluation of artefact and monitor the status of worthwhile outcomes and adverse experience. This was the first substantial use of such a table.

These resources were generally a response to the design problem that was partially understood at the time but later refined through reflection. The resources themselves were revised and adapted to make them work for this specific research situation. This produced new reusable resources. All resources can be found at:

<https://resourcesbyjennifergeorge.wordpress.com/>

10.5. Disability Care Context

Preliminary research showed that beneficiaries were already using various tools and processes for the purpose of communicating with the care circle members. This led to the proposal for an AT focused choice and use tool. The feasibility study in Chapter 4 shifted the design agenda from an AT focus to social support system, that could be accessed by all members of care circles, for not only choice and use of AT, but for a more holistic care of individuals with disabilities. This shifted the purpose from *choice and use* of AT to *choice and leave to use* and extended it to support capability and disability, providing a broader concept of AT that was in line with the ICF. This led to the design and implementation of a social support system, that met the needs of the potential users. This was the evolution of the initially recognised problem space together with its solution space.

Chapter 3 identified SEN as limited in number of care circle members being 2-3 and support being limited to the context of education. NHS involved family members and medical practitioners and supported home and educational environment but not additional activities. ACE Centre provided a well balanced support but was expensive. There is neither limitation in care circle membership or environments in My Care Circle (MCC). It is also a free service.

MCC thus bridges the gap between practices across different environments and has the potential to extend to international guidance and policies that could be guided by this practice.

If as many participants as expected were recruited, providing IT training to care circle members would not have been within the scope of this research, albeit that is what would have made a STS. However, as fewer users were recruited, providing IT support was possible.

Evaluation of Version 1 of MCC showed that there is potential benefit in the use of this social support system. Evaluation of Version 2 showed that the worthwhile experience recorded in the worth sketch had increased and adverse experience had been reduced for those who have used them. Element measurement table Version 2 and worth sketch Version 4 showed how the design artefact moved the design situation from current towards ideal. While a thorough RtD process was conducted and the design artefact developed, it was not possible to establish if the artefact was completely successful due to the lack of participant recruitment. More concrete statistical evidence would be needed to strengthen a claim for a disability care contribution further. This is likely to be done within an institutional infrastructure for recruitment of users who are currently working with different charities and disability support centres. For the service was to run continuously, sustainable investment would be needed for development.

It is however worth noting that participant recruitment was identified as a risk for research and design at the beginning of Chapter 6. While based on the qualitative feedback from current participants, it is clear that the overall outcome of MCC is positive, but more participant recruitment is needed to strengthen this with quantitative verification.

Based on the features that were specified, but not developed, and findings from user testing in Iteration 6, development of Version 3 of MCC would need to include the following.

- Access and privilege features that the legal primary carer has control where they could decide the access and privileges for the members in their care circle individually or generally;
- Alert feature for emergencies that will inform care circle members that another member looking for some advice or support;
- Planning for members recruiting sufficient members to obtain quantitative data;
- Having a sense of assurance that this is not merely a study, but the knowledge and capabilities would be maintained for several years in some way.

10.6. Next Chapter

This chapter reflected on the entire research process, analysed the research approach at paradigm, methodology and resource levels and also looked at how the requirements of the design context has been satisfied. The next chapter provides a summary of the thesis, lists the original claims for contribution to knowledge, states the limitations and suggests any future work.

Chapter 11 - Summary and Conclusions

Preliminary research showed there has as yet been no full development and assessment of worth-focused approaches that are compatible with a broad range of design and evaluation practices. The research problem addressed in this thesis is the gap in understanding as to whether and how a worth-focus can be maintained throughout a Research through Design (RtD) process by:

1. developing new worth-focused RtD approaches through a case study focused on an important social problem, disability; and
2. documenting and assessing the effectiveness of the approaches in the context of a challenging design case study, and thus make a methodological contribution to the emerging area of RtD.

This chapter opens with an overall summary of the activities involved. It then sets out how this research has made an original contribution to knowledge and states claims based on the analyses in Chapter 10. Thereafter, it provides the conclusions from the research, which respond to the research questions. Finally it makes recommendations for future activities following on from this research.

11.1. Summary of Research

The research problem stated in Chapter 1 was the lack of an assessed and complete RtD process with worth focused activities. This research used the context of assistive technology, which involved a particularly challenging design setting, in addition to fast moving developments in interface design domain, as the basis for a case study of an RtD process.

Chapter 1 explained the decision to choose the ICF model of disability as the conceptual framework for understanding disability for the purposes of this research. It then provided an overview of the potential research approach: Research through Design (RtD) process with a strong worth-focus where *beneficiaries*, *evaluations*, *artefacts* and *purposes* (design arenas) were continuously progressed with Total Iteration Potential (TIP) and progressive instantiation. The focus and connections between these design arenas were continuously iterated, resulting in an integrated methodology. Research questions, original contributions

with claims, and an overview of the structure of the thesis were provided. Finally, there was a statement addressing ethics of the study.

Next, Chapter 2, explored a variety of research paradigms, methodology and methods that could potentially direct and support the research, reaching the conclusion that in an RtD approach, a plan for the entire research cannot be made at the outset, but evolves via reflection. Action Research as RtD (which must include reflection) that includes both primary and secondary research was chosen. It was decided that reflection stops would be made after every few activities to consolidate each iteration.

This was followed by Chapter 3, which set out in detail the design context of disability, with reference to secondary research. This explored disability models, AT devices for various disabilities, assessment methods and relevant legislation. The chapter focused on design choices relating to *artefact*, *purpose* and *beneficiaries*. At the end of this chapter, the first reflection stop was made to mark the start of the first creative design iteration in Chapter 4, where the strategy for Iteration 1 was explained.

Chapter 4 (Iteration 1) started with consideration of an automatic Decision Support System (DSS) that could be programmed to recommend AT devices by reference to a specific biomedical condition and the type of task that needed to be undertaken. This activity focussed on a potential *artefact* that could meet the needs (*purpose*) of potential *beneficiaries*. This was followed by three activities that increased understanding of *beneficiaries*, *purpose* and *artefact*. Firstly an interview at an assessment centre for disability support (referred to as ‘the Centre’), then an observation at a special needs school and further interviews, and finally a personal reflection on my experience with a child with severe motor impairment, were conducted. This helped to identify who the decision makers are in relation to choice and use of AT, which influenced the envisaged purpose of the design solution. The findings of these studies ruled out the possibility of DSS as a viable intervention, but suggested that it would be worthwhile to explore the feasibility of a social support system, which could better meet the identified needs. A Worth-Integration Table that connected the findings from the iteration was introduced, which was an original contribution to knowledge. A reflection stop was made at this point to identify activities for the next iteration, where a further literature review on Socio-Technical Systems and primary research (interviews and discussions), and an application of the CAT model to existing social media were planned.

Chapter 5 (Iteration 2) started with an exploration of Socio-Technical Systems (STS), where the technical systems are understood in their usage contexts. While a variety of features were identified as useful for the potential *artefact*, it was decided that a social network with information resources would be required to meet the *purpose* identified so far. The concept of a social network with information resources was evaluated with a family member of a disabled individual and professional care circle members. This assessed the potential of such an *artefact*, and explored further *purposes* and *beneficiary contexts*. A further activity involved use of Hersch and Johnson's (2009b) CAT model to study the viability of six existing social networks as potential design solutions, especially technical accessibility. This was followed by exploring the developing of a social network using an existing framework, Ning, but its unsuitability led to looking for a developer early in the process.

The CAT model was the first time that a design choice was made about *evaluation* with connections to *purpose*, *beneficiaries* and *artefact*. Iteration 2 thus focused on *beneficiaries* and potential design *purpose*, and then co-ordinated these with a focus on a second possible *artefact*. Thus, the CAT model application and the implementation of Ning, co-ordinated the *evaluation* for an *artefact* with acquiring further positive options for design *purpose*, as well as negative options that needed to be designed out. This process also helped to identify benefits, costs and any adverse consequences through the use of an Artefact Connection Table (Table 5.3), which was an original design resource and thus a new contribution to knowledge. This iteration ended with a Worth Integration Table that extended integration beyond the first iteration.

The aim of Chapter 6 (Iteration 3) was to confirm the requirements of the envisaged informative and collaborative social support system. Chapter 6 started by analysing the findings from all activities in Chapter 4 and 5 and structuring them into Worth Shift Tables. This translated into a worth sketch based on the understanding of the *purpose*, *beneficiaries* and potential *artefact* so far. A questionnaire was devised based on the information elicited using the Confirmation of Assumptions and Missing Information Table. It was piloted and thereafter fielded with potential care circle members. Based on the findings, the worth sketch was revised. Next, the findings needed to be organised in a way that informed the design and development of the *artefact*.

Chapter 7 (Iteration 4) started with the design of three worth-focused personas that represented the user groups for the envisaged *artefact*. They were built using the responses to the questions in Iteration 3 and supported the requirement specifications for the *artefact*, a website with social networking capabilities. Development of a website to meet these requirements was outsourced and thus Version 1 of the research *artefact* My Care Circle (MCC) was developed. The personas were focused on *beneficiaries*, *purpose* and the *artefact* while the requirements, design and development were entirely *artefact* focused. The reflection stop here planned the *evaluation* of the *artefact*.

Chapter 8 (Iteration 5) evaluated the artefact developed in Iteration 4 through a Cognitive Walkthrough using the three personas, expert evaluation by two practitioners, and think aloud usability tests. A further activity was carried out to assess if the *purpose* for potential *beneficiaries* and *artefact* were still relevant. Thereafter, the findings from the *evaluations* were used to develop Version 2 of the *artefact* (available at www.mycarecircle.co.uk).

Chapter 9 (Iteration 6) introduced the artefact to real world users and started by defining the evaluation plan. However, it proved impossible to recruit a sufficiently large sample of participants. This chapter, however, reported on the co-design of the content for the website by the researcher and a GP and thereafter the continuous feedback and development on the website.

The next section sets out the claimed contributions to knowledge based on the analyses of the RtD process presented in Chapter 10.

11.2. Claimed Contributions to Knowledge

This research responded to the overarching research question:

What are the realities of Research through Design with a worth-focus, Total Iteration Potential and reflection guided by the Working to Choose framework?

Chapter 10 reflected *on* the research process, its outcomes and discussed the contributions it makes to knowledge. This section concludes this analysis by presenting claims for contributions to knowledge.

11.2.1. Claim 1

Reflection *on* Action, a requirement of Research through Design along with appropriate tracking, can be made more productive and effective through conceptual structures that expose the structure and overall content of design work, i.e.: MADS, PADs, Iteration Shift Tables, and DAP lists.

This practice-based research case study has integrated previously separate aspects of Cockton's development of abstract structures (Cockton, 2005, 2010) and properties for design work (Cockton, 2009). It also extended these conceptual structures of design as the approach to reflection itself evolved. This reflection supported and extended application of progressive instantiation from meta-principles (Cockton 2009) to design arenas, and demonstrated the research process through which problems and solutions were progressively framed.

Cockton (2010) introduced Abstract Design Situations (ADS). This research reported in this thesis exposed the need for a hierarchy of ADS and introduced four levels of detail, Most Abstract Design Situation (MADS), Proportional Abstract Design Situation (PADS), Iteration Shift Tables, and Design Arena Progress (DAP) lists.

Two successive MADS can indicate whether a design arena or connection was added, removed or persisted between design research iterations (Figure 11.1).

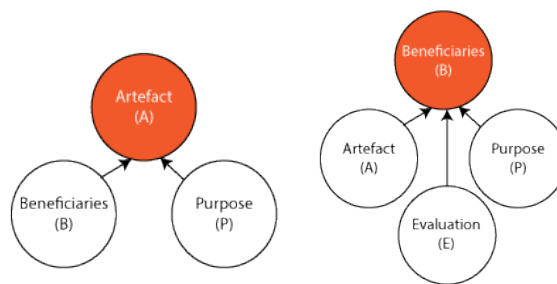


Figure 11.1 - Example of two successive MADS (Iterations 1 and 2)

Two PADS ('before' and 'after') can compare the extent of anticipated and actual design moves within a design research iteration (Figure 11.2).

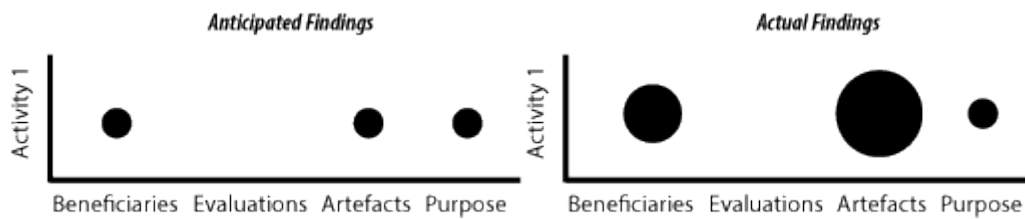


Figure 11.2 - Example of PADS

Iteration Shift Tables, which summarise how the understanding of each design arena shifted, are introduced in this thesis (Table 11.1).

Table 11.1 - Example Iteration Shift Table

	From	To
<i>Artefact</i>	Choice and use model for decision support tool	An embryonic comprehensive platform for multiple benefits including features for social networking.
<i>Beneficiaries</i>	Immediate family and child	Care circle and additional stakeholders, and child
<i>Evaluation</i>	No evaluation in mind	Feasibility of potential DSS was considered and discarded
<i>Purpose</i>	Support selection and use of AT for a child	Support multiple benefits; plus adverse outcomes to avoid, and costs to reduce

Lists of new findings or options for each design arena (evidencing progressive instantiation) are called Design Arena Progress (DAP) lists, and were also introduced in this thesis.

- *Beneficiaries:*
 - B13: The design artefact should assist inexperienced, non-professional carers (such as parents);
 - B14: Should include social workers;
 - B15: It should include additional care circle members.
- *Artefacts:*
 - A20: Should not impose standard care circle. This must be custom built (*directive*);
 - A21: It should communicate understanding of the disabled individual's capabilities, needs, care circle membership and practices, including informal assessment by legal guardians;
 - A22: Provide initial support together with facilitation of assessment for disability intervention in a familiar environment;
 - A23: It should provide information on methods of communication to the care circle;
 - A24: It should provide information on a wide range of assessment agencies, as well as on devices and assessment and funding procedures.
- *Purpose:*
 - P6: It should make visits of professionals (e.g. social workers) more effective.

Figure 11.3 - Example of DAP lists

MADS, PADS, Iteration Shift Tables, and DAP lists are all original contributions of this research, and were recorded at the end of each iteration, and structured the detailed tracking of the research through design process. Cockton's resource function vocabulary (Cockton, 2013b) has also been used to structure reflection. ADS related structures and resource functions can thus be used by critical design researchers to address issues concerning the nature of reflection in design research. The four levels of ADS (MADS, PADS, Iteration Shift Tables, DAP lists) and Resource Function vocabulary were used to support claims in this research both progressively, and via retrospective overview. For example, MADS and PADS were used to track primary generator (Claim 3), and MADS are used to support Claim 4.

Initially Cockton's Meta-Principles were used in attempt to reflect and track activities that occurred at each stage, but this was of limited value. In 2012, Cockton introduced resource functions in his Working to Choose (W2C) Framework, where he argued that meta-principles are realised through resources. This resulted in resource function vocabulary replacing meta-principles in this thesis for predicting the function of resources and reflectively evaluating each resource used and each iteration, exposing creative and reflective design research expertise. Resource functions provided more effective support for reflection than meta-principles.

Schön (1983)'s study of reflective practitioners has been influential in education, health and social care domains. However Cross (2011, p.23) observed that, for such an influential study, Schön's example was only based on a partial activity that was derived from conceptual practice of architecture within education. This meant that the influential study was not backed up with extensive evidence.

The significance of this thesis' first claim is that it responds to Cross's critique by providing detailed evidence for Schön's claims on the role of reflection in design research. This evidence was gathered in the real context of designing to address a social problem, i.e. disability, and was recorded over six iterations, demonstrating reflection *in* and *on* an Action RtD process.

11.2.2. Claim 2

The second claim is that while it was known that Frayling's Modes for Research in Art and Design may combine in several ways, detailed evidence is provided by this research that reveals in detail how all three modes interact with each other. Yee (2009) noted that Frayling's (1994) categories of design Research *into*, *for* and *through* design are not mutually exclusive. This claim is significant as it is based on more detailed and extensive evidence than in Yee's analysis. This evidence shows how research *for*, *into* and *through* design continuously combined and diverged as shown in Figure 10.2 (repeated below as Figure 11.4).

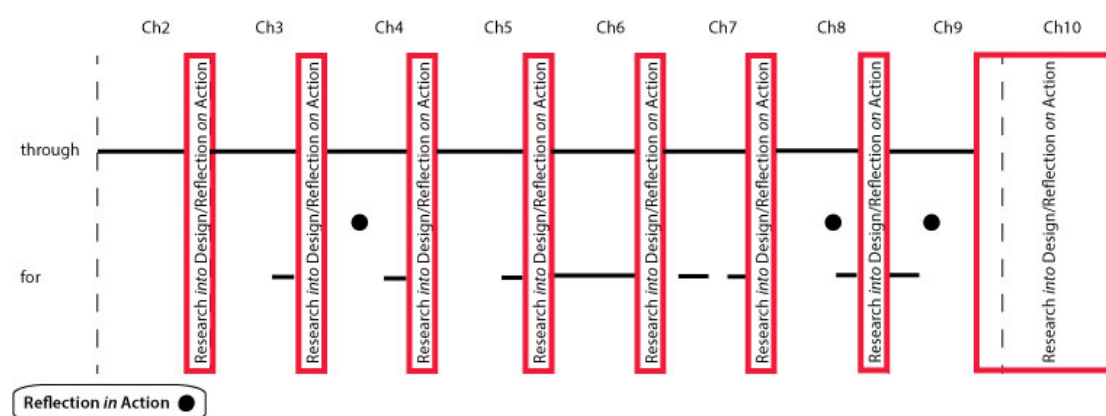


Figure 11.4 (repeated) – Research through, into and for Design and Reflection in and on Action Process.

The research mode moved to Research *through* design (RtD), each time a design move was made, repeatedly until the artefact was fully realised. This starts with Chapter 4 (Activity 0)

where an initial concept was documented and after further information gathering in Chapters 4 and 5, an existing framework was tested Chapter 5 (Activity 8). This eventually led to Versions 1 and 2 of My Care Circle through several interim activities. The extent and content of the recording, tracking and recovery (post-hoc) of the design research work enabled reflection, guided by the W2C framework. Design moves were thus achieved within the Research *through* design (RtD) mode, but these were continuously interleaved with the other modes.

Research (with both a small r and large R) *for* design occurred at different points in the research. The former was necessary to progress research through design, but (by definition) did not result in original contributions to knowledge. Research (with a small r) *for* design began in Chapter 2 where design models, design theory, practice and achievements were explored; Chapter 5 (Activity 5) reviewed the STS literature, and in Chapter 10 and this Chapter (11), literature was revisited to form claims. There was also research *for* design in Chapter 3, where the case study context was reviewed including disability models, existing choice and use models for AT, disability assessment approach, AT devices and existing legislation and guidance. The process of determining the suitable design solution with primary research (such as interviews, a survey, design refinements, and evaluations) was also research *for* design.

Research (capital R) *for* design by definition has to result in original contributions to knowledge. These largely take the form of novel and adapted approaches and resources for worth-focused interaction design: Worth Integration Tables, Artefact Connection Tables, Worth Shift Tables, Worth Focused Personas, Worth Focused Questionnaire Design, Persona based Cognitive Walkthrough and Element Measurement Tables. In addition, MADS, PADS, Iteration Shift Tables, and DAP Lists provide original support for research through design, and thus make further original contributions to knowledge for the design research process (Claim 1 above) and for the application domain of disability (Claim 6 below).

The corpus of data produced as a result of the activities (from both research *for* and *through* design) provided a focus for research *into* design (with both a small r and large R) within this thesis. This research (small r) analysed the data to increase the understanding of each intermediate design situation, steered it towards a suitable design solution, and confirmed whether it could indeed move the current social situation towards something more ideal. This

added considerable depth to reflective activities. Research into design (large R) resulted when original contributions were made to knowledge (Claims 1, 3 and 4). This was mostly summarised in Chapter 10.

11.2.3. Claim 3

Research through design is a research methodology that is structured around creative design work, which is understood as being design led. Darke (1979) argued that a design process followed a *generator-conjecture-analysis* structure, with the artefact design arena driving the design process throughout. This thesis has demonstrated that in a multi-disciplinary design context, design generators are complex, dynamic and short lived, as revealed by appropriate tracking. This is significant because it challenges Darke's position on creative design work. There are progressively shifting complex generators rather than a single constant primary generator. More than thirty-five years after Darke's seminal study, *primary generators* within design contexts have been shown to be more complex, and her theory is thus extended beyond a single design arena. While *conjectures* do lead artefact design activities, complex *generators* have to be recognised retrospectively through reflection. However, Figure 10.3 (repeated below as Figure 11.5) showed that the anticipated generator could not turn out to be the actual primary generator.

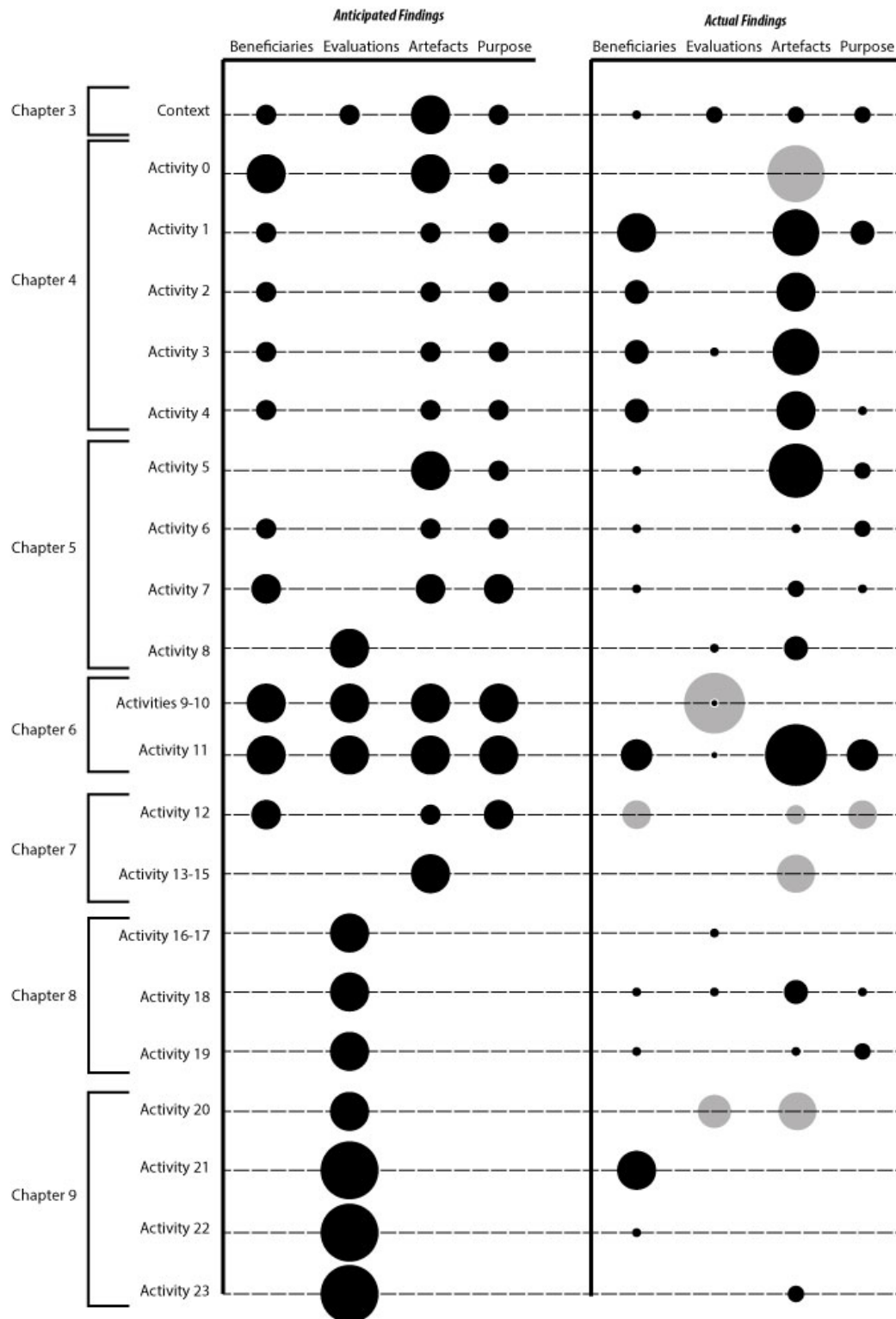


Figure 11.5 (repeated) – Balance and Realities of Design Arena Overviews

Complex, dynamic and short lived *generators* also challenge all existing ‘centric’ approaches to design research and practice. The tracking of the RtD process exposed *balance* and *integration* of design arenas as an alternative to research being centred or focused on a single

arena. Figure 10.2 showed the tracking of each iteration's design arenas. This is significant as existing design research has been user-centred (beneficiaries- or evaluation-centred) or artefact-centred. For example, Verganti's (2009) design-led innovation is an artefact-centred paradigm. Similarly, Camara *et al.*, (2013) used worth-centred approaches in the context of engineering design, another artefact -centred paradigm. Engineering design methodologies are also *normative* and prescribe what researchers should do, rather than embracing descriptive and reflective approaches that match the realities of design (research) in practice.

Complex dynamic generators extend Keller's (2005) research, which showed at a very high level how theory, practice and technology can parallel and influence each other. This research takes a broader detailed approach where all four design arenas are balanced and integrated, making it the first detailed documentation of a fully 'post-centric' approach with no assumptions about an imposed pre-defined process. Also, the concept of *worth* supported much of the integration. Understandings of design purpose as worth were related to user studies, artefact features and evaluation measures.

11.2.4. Claim 4

Total Iteration Potential is more complex than in the Value-Centred Design Framework (Cockton, 2005) and requires full parallelism, as revealed by appropriate tracking.

As seen in Chapter 3 (Section 3.2.2 Sequential Methodologies), Gould and Lewis (1985, 1991) proposed an early and continual focus on users throughout the design process. The classic user-centered, contextual design approach process is Research-Design-Evaluation-Iteration-Redesign-Evaluation-Iteration-Redesign-Evaluation-Iteration, etc. Cockton (2005) introduced Value-Centred Design (VCD) framework (Figure 11.4) to keep iteration and evaluation separate and evaluate outcomes instead of systems, but the process itself did not fully relax the sequential constraints of early user-centred design.

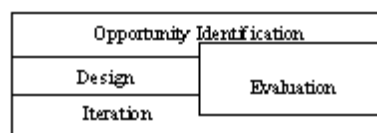


Figure 11.6 - VCD process structure (Cockton, 2005)

In contrast to the process structure in Figure 11.4, the actual design and evaluation activities for this thesis required spontaneity, opportunism, confirmation of assumptions (once they

have been identified), and responsiveness to the evolving design problem, resulting in a shifting focus on one or more design arenas (*beneficiaries, evaluations, artefact* and *purpose* at various times. There were reflective stops at the end of groups of activities (iterations) that took stock of the progress made with each design arena, and this directed the research. This showed that a single centred focus is not necessary and that it is in fact better to plan the focus with each iteration and recognise shifts in foci in each stage of the research, thereby being post-centric. It also showed that beyond the start and finish of the process and reflective stops, there were no, and could not be any, set structures to the process other than the (potentially infinite) limits of a MADS structure.

This is thus the first demonstration of truly Total Iteration Potential (TIP). This is significant as it demonstrated and extended Cockton (2005)'s position on TIP as largely iterating between design arenas. For example, the understanding of the possibilities for TIP (Cockton, 2010) were extended by recognising loops where *evaluation* is *evaluated* or where connections form between some aspects of *artefact* and others.

11.2.5. Claim 5

New Worth-Focused (Wo-Fo) approaches and resources have been developed and combined effectively in a challenging case study, as evidenced by appropriate tracking. The novel resources created or adapted are:

1. *Worth Integration Tables*, used in Chapters 4 and 5 used to map requirements of My Care Circle against design arenas (original);
2. *Worth Shift Tables*, used to map current situation to ideal situation for design Questionnaire in Chapter 6 (original);
3. *Artefact Connection Tables*, that were used to map envisaged increased benefits and reduced costs/aversion/lack to artefact features in Chapter 6 (variation to feature-benefit table from Griskscheit, *et. al.*, (1993));
4. *Worth-focussed questionnaire design* in Chapter 6 (original);
5. *Worth focused Personas* in Chapter 7 (adaptation from Olsen, (2004)), used to bring together all findings from preceding activities, produce requirement specifications, and be subsequently used for Cognitive Walkthrough (Chapter 8, adaptation);
6. *Element Measurement Tables* in Chapter 9 (original).

These are published with tutorial support at <https://resourcesbyjennifergeorge.wordpress.com/> and will be useful for worth-focused design researchers and practitioners.

These are all the results of Research *for* design. The significance of these resources lies in their range (above) and their integration and co-ordination within a full case study. While Otero (2009); Zaman and Abeele (2010); Camara, *et al.*, 2013; Cockton *et al.*, (2009a); Cockton *et al.*, (2009) used worth sketch and maps, user experience frames and worth boards within state-of-the-art projects, existing evaluations of worth-focused approaches have not been related to a full design process. Existing reports of worth-focused approaches are restricted to the use of single methods, either to identify potential design purpose (as worth), or to co-ordinate this with identified options for designed artefacts (Muyllé, (2009); Gutman and Reynolds (1979); Cockton *et al.*, (2009a), Jose and Otero (2011), Camara, *et al.*, 2013; Kampurri, (2011)). However, none of these researchers have documented the design process completely. In contrast, this practice-based research developed a worthwhile social support system through the evolution of an extensively documented worth-focused design research process.

11.2.6. Claim 6

The sixth and final claim is that My Care Circle Version 2 is a well-developed basis for future STS development through sustainable sponsored service design and implementation.

This is significant because this demonstrates a social approach, rather than a biomedical one, that uses the ICF model. It provides an evaluated system that can be used to build a more sustainable STS.

In addition, consistent with a definition of RtD that focuses on the production of knowledge for the world (Zimmerman, *et al.*, 2007), the process produced several insights into the application context that can be reused by researchers, as well as the design of My Care Circle Version 2, which can inform future social innovation in support of care circles for children with major impairments.

11.3. Limitations of this research

This research process focused on care circles of individuals with disabilities. The care circles formed would be context specific. However, the scope of this case study was limited to the UK. Should this study be extended abroad, cultural differences in approach to disability and regional resources would need to be identified and integrated to establish viable STSs.

Another limitation worth noting is that the development of My Care Circle (MCC) was carried out by a single individual within a small budget that resulted in a slow progress including poor design in Version 1. Participant recruitment was also carried out by the researcher through individual personal contacts, which resulted in limited number of independent users of MCC. An effective service design delivered to develop a financially sustainable STSs and recruit participants would potentially provide a more robust system and the recruitment of participants.

Cockton's research (2005-2014) was a moving target with outputs relating to value-centred, worth-centred, worth-focused together with meta-principles and ADS to resource functions. The research also shifted from an engineering approach to one that celebrated creative design processes. While this moving target was not a limitation to research, it proved to be a challenge to keep track the development of Cockton's research and to identify how this research contributes to it.

This PhD had several resources and reflections implemented retrospectively. Fast moving research was a challenge and meant repeatedly revisiting previous activities and retrospectively making changes. As a result reflection *in* action could not be planned and used for any activities that were recorded in retrospect.

11.4. Possible Future Work

The case study's main objective was to provide support for the care circles of individuals with disabilities. Socio-technical perspectives were first developed in ergonomics, but most work in a socio-technical tradition has occurred within the field of information systems (Activity 5, Chapter 5). The scope of a STS and its activities extends beyond designed (technical) artefacts to include all stakeholders in the system's operation. The more recent term Socio-Digital System (SDS) is a response to the now pervasive nature of digital

technologies, where users can interact with multiple devices during multiple activities. Rather than there being a single technical system that is clearly separate from its human beneficiaries, the social and the digital are closely intertwined in contemporary SDSs. Chapter 5, (Activity 8) saw the CAT model used to review existing social media platforms for suitability for this case study by the researcher. Hersch and Johnson (2009b) intended the tool to be used for choice and use of AT for an individual. This took the CAT model beyond the individual researcher to a model that involved the collaboration with entire care circle. Further, this research also extended the CAT model by an additional column for explaining the decisions.

Lean UX (Gothelf & Seidon, 2013) is an Agile approach that unites business and development with design and focuses on capturing thoughts about processes by conversation with customers, analysing them and using the findings to solve problems. Lean UX can also test hypothesis, but is entirely practice based. RtD is a more rigorous approach that can also be used for testing hypothesis. Lean UX will benefit from exploring this case study to understand how RtD could potentially improve Lean UX practice.

Future work is primarily required within the chosen case study where funding could potentially improve the design artefact and also better recruit for evaluation and usage. It could be even more beneficial if it has a credible sponsor who can persuade participants to invest time and effort. This would also address the limitation of the current research where further statistical evidence is needed to strengthen claim of disability care contribution (Claim 5) further. In addition, it would also benefit from the development of a suitable web or mobile application.

Giving disabled individuals the same access and rights as anyone else drove and motivated this research. The focus was to improve their current situation towards what they consider to be ideal and a significant shift has been made.

11.5. Conclusions

Based on the responses to the research questions, the conclusions of this study are as follows.

- The research process demonstrated how research *for*, *into* and *through* design combined in a practice-led design process.

- Design arenas, connections, anticipated design arenas and actual ones, and the findings for each arena at the end of each activity were tracked in detail which demonstrated and unearthed several findings.
 - They were used to Reflect *on* action at the end of each iteration and then again at the end of the process;
 - It demonstrated that design does not require to be centred or focused but instead needs to be balanced;
 - It also showed that the anticipated balance of design arenas can be different to those actually realised;
 - Tracking showed that the activities, while at times planned to be sequential, were usually parallel, either in being carried out or in the focus on design arenas;
 - This also realised in practice that without a parallel methodology and process reconfiguration TIP was not possible;
 - Resource Function Analysis is a viable framework for reflection;
 - It introduced four new levels to the ADS spectrum; MADS, PADS, Iteration Shifts and DAP lists.
- This research produced several new worth focused resources: worth integration tables, worth shift tables, worth focused questionnaire design and worth focused personas as contribution to design.
- The research made a care contribution by producing knowledge through the process of developing a worth focused design artefact that could meet the needs of identified care circles.

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Appendices

GUIDE TO THESIS

A CASE STUDY OF BALANCE AND INTEGRATION IN WORTH-FOCUSED RESEARCH THROUGH DESIGN

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June 2016

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1. Introduction

Along with introductory and concluding overviews and analyses, this thesis records activities and reflections of six iterations. These iterations repeatedly use several novel methodological concepts to present information and to aid critical reflection. These iterations also created several new concepts that complement and extend existing design research concepts. The thesis is from Introduction to Conclusion 359 pages long. Some of these concepts are explained in Chapter 2 and others are new concepts introduced within the chapters. While they are used consistently over Chapters 4-9, it can be challenging for the reader to continuously remember these concepts.

A guide to a thesis is common practice in practice based and publication based PhDs. This is neither, but is still a complex design PhD that can benefit from a guide. This guide was created to assist the reader with reminders of what each methodological concept is and what each reflection on an iteration achieves with it. A Glossary of these terms is also provided at the end of this Guide.

This guide further provides an aerial view of the overall thesis structure to understand the design moves made in each chapter. Chapter 1 introduces the thesis. Chapter 2 reviews the core subject of this thesis, research through design and related approaches. This is followed by reviewing the literature available on the chosen research context in Chapter 3. Chapters 4-9 report the activities carried out as part of the research process and reflects on each iteration. Chapter 10 analyses all findings to arrive at conclusions. The final Chapter 11 summarises all chapters and makes claims for original contribution to knowledge and concludes this research by setting out future worthwhile research directions.

The recommended order of reading the thesis and guide is as follows:

1. start by reading Chapters 1-3;
2. read this Guide;
3. read Chapters 4-9 referring to this Guide as needed and
4. read Chapters 10-11.

2. Structure of Iteration Chapters 4-9

Chapters 4-9 record 6 iterations that document the 23 activities and have the same structure. They apply an expanding set of theoretical concepts and representations for reflection that are elaborated in the next section of this guide (e.g., *DAP lists* in [Section 3.1](#)).

These chapters start by **reporting** on up to 5 activities, each of them concluding with *Design Arena Progress (DAP) list* ([Section 3.1](#)), which is the most concrete summary of *design moves* (*terms in italics* are listed in [Section 5, Glossary](#)). After the activities have been reported, a chapter ends with a summary of the iteration and a **reflection**, structured as follows:

- Order of activities ([Section 3.2](#))
- Scope of the iteration ([Section 3.3-3.4](#))
- Progress in iteration ([Section 3.5](#))
- Realities of resource functions ([Section 3.7](#))
- Discussion of the next iteration ([Section 3.4-3.5](#))

This structure applies to Chapters 4 to 9, which report on the design research activities as follows.

Chapter 4 (Iteration 1) starts by recording Decision Support System as an anticipated solution. The potential for such a DSS is explored by exploring the design context in detail by 4 primary activities. This iteration concludes with a potential for a social support system.

Chapter 5 (Iteration 2) started by returning to literature to explore Socio-Technical Systems (STS) and decided a social network with information resource would be require to meet the purposes identified so far. Further primary activities were carried out to refine this information further.

Chapter 6 (Iteration 3) starts by analysing the findings so far and goes on to refine them by designing, piloting and fielding a questionnaire. The questionnaire is used to confirm existing information by a larger group of participants and identify any missing information.

Chapter 7 (Iteration 4) records design activities carried out in this iteration that lead to the development of a social network with information resource, named My Care Circle.

Chapter 8 (Iteration 5) records the evaluation of My Care Circle using personas, experts and limited number of users. Subsequently, Version 2 of My Care Circle is built.

Chapter 9 (Iteration 6) started with the development of an evaluation plan following which My Care Circle is iteratively evaluated by real world users.

3. Visuals used in Iteration Summaries and Reflections

This thesis uses tables and other visual representations to present and analyse information and reflect on its findings. The purpose of each type of visual and its contribution to the thesis is explained with examples in this section.

The visuals in this section occur in the reflection part of the iteration Chapters 4-9.

3.1. Design Arena Progress (DAP) List

This list, referred to as the DAP list, is used to present findings from each activity against *design arenas*. DAP lists are numbered and used to track new findings from activities.

- *Beneficiaries:*
 - B13: The design artefact should assist inexperienced, non-professional carers (such as parents);
 - B14: Should include social workers;
 - B15: It should include additional care circle members.
- *Artefacts:*
 - A20: Should not impose standard care circle. This must be custom built (*directive*);
 - A21: It should communicate understanding of the disabled individual's capabilities, needs, care circle membership and practices, including informal assessment by legal guardians;
 - A22: Provide initial support together with facilitation of assessment for disability intervention in a familiar environment;
 - A23: It should provide information on methods of communication to the care circle;
 - A24: It should provide information on a wide range of assessment agencies, as well as on devices and assessment and funding procedures.
- *Purpose:*
 - P6: It should make visits of professionals (e.g. social workers) more effective.

The number of findings for each design arena is used within subsequent integrative activities.

3.2. Order of Activities

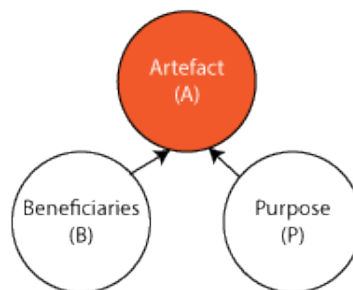
Activities at times happened at times different to when they were analysed and recorded within the thesis. These tables record the order in which the activities actually happened.

Chapters 2 & 3		Chapter 4: Activities 0-4
January 2009		Activity 4: Experiential study documentation
March 2008	AT	
August 2012		Activity 0: Envisaged Artefact

These tables are used at the end of each iteration to reflect on the sequence and duration of activities and demonstrate the parallel methodology. A full tracking of activities is also provided in Appendix C10.

3.3. Most Abstract Design Situations (MADS)

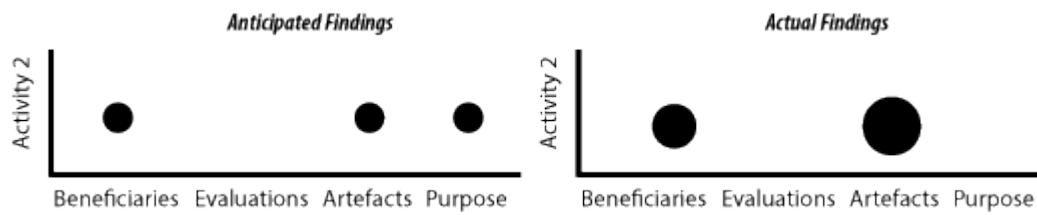
This is the most abstract view of *Abstract Design Situations (ADS)*. These visuals show which design arenas and connections were active within the activity or a group of activities.



Individual MADS helps visualise the primary generator of the activity and collective visualise the shift in primary generator, design arenas and their connections and demonstrate Total Iteration Potential.

3.4. Proportional Abstract Design Situations (PADs)

This is more concrete than a MADS and is the second level of ADS. The anticipated and actual proportional findings from each of the design arenas in each activity are presented using these visuals at the end of each iteration.



PADS are used to reflect on realities of design moves and quantify them whenever possible. The actual findings also reflect the number of findings from Section 3.1.

3.5. Iteration Shift Tables

These tables record the shift in the understanding of each design arena within an iteration.

	<i>From</i>	<i>To</i>
<i>Beneficiaries</i>		
<i>Evaluation</i>		
<i>Artefacts</i>		
<i>Purpose</i>		

These tables are used twice within each iteration. In the 'Reflection' section, these tables summarise the shift made within the iteration and in the 'Next Iteration' section, record what was anticipated in the subsequent iteration. This included new information that was acquired in the iteration and shifts in the current understanding. It is also used to show how the anticipated design moves compared to reality.

3.6. Realities of Resource Functions

Chapter 2 listed Potential Resource Functions. At the end of each iteration, a Resource Function Analysis (RFA) was carried out and achieved functions for each of the activities from within the iteration are presented.

Activity	Resource	Achieved Functions
Activity 9	Questionnaire Design	Expressive, Directive, Protective
Activity 10	Questionnaire Pilot	Expressive, Informative, Inquisitive Protective, Directive
Activity 11	Questionnaire Fielding and Analysis	Expressive, Informative, Inquisitive, Protective

Cumulative Functions		Informative, Expressive
----------------------	--	-------------------------

This table at the end of each iteration compares anticipated functions against reality. In addition, the cumulative functions of the iteration are also recognised.

4. Other Non-Repetitive Tables

4.1. Chapter 2 - Potential Resource Functions

Based on the literature review, functions of the existing resources that were used to carry out activities were categorised as primary, potential and unlikely functions.

Resource and Activity Nunber	Primary Function	Potential Functions	Unlikely functions
Desk/Secondary research (Chapter 3, Activity 5)	Informative	Directive Adumbrative Ameliorative Invigorative Integrative Protective	Expressive Inquisitive Performative

This information was used at reflection points at the end of iterations to compare against actual functions ([Section 3.6](#)). This subsequently contributes to the Resource Function Analysis (RFA) carried out in Chapter 10.

4.2. Chapters 4 and 5 - Worth Integration Table

These tables can be found at the end of Chapters 4 and 5. Once the activities in iterations recorded in these two chapters were carried out, the worth components (Beneficiaries, Evaluation, Artefact and Purpose) from the [DAP list \(Section 3.1\)](#) identifications are documented and connected to understand risks or adverse consequences.

<i>Artefact</i> features and capabilities under consideration	Related <i>Purpose</i> (Benefits)	Potential <i>Beneficiaries</i>	Risks of increased costs or adverse consequences	Activity No. (Source)
---------------------------------------------------------------	-----------------------------------	--------------------------------	--------------------------------------------------	-----------------------

<i>Provide peer supports about AT amongst care circle members (A5)</i>	Sharing experience and recommendations	Child & care circle	None	2, 3
------------------------------------------------------------------------	----------------------------------------	---------------------	------	------

4.3. Chapter 6 - Worth Shift Tables

Using the first Worth Sketch (Appendix C6), that captured findings related to worthwhile outcomes, worthwhile experience, qualities, features, materials, adverse experience and adverse outcomes, this table is used to recognise the current and ideal situations. This is based on worth, i.e. increasing benefits and reducing adverse outcomes. Adverse outcomes in this case may also mean costs and aversions. They are listed as current situation and the ideal situation.

Current	Ideal
Cannot participate in all meetings (cost)	Access to all information from meetings even <i>when they cannot personally attend</i>
Time and distance limitations (cost)	Being able to communicate from <i>anywhere with internet access.</i>

Once they have been listed, they are also prioritised in order of impact on care circle members.

4.4. Chapter 6 - Artefact Connection Table

These tables connect between worth components recognised in the [Worth Shift Tables \(Section 4.3\)](#) and potential artefact features. Artefact features are identified to both improve benefits and also reduce costs and aversions.

Improved Benefits for <i>Beneficiaries</i>	Potential <i>artefact</i> Features
No additional time needed for full disability assessments	Progressive assessment uploads
Less challenging to arrange times for all <i>care circle members</i>	Synchronous and asynchronous usage, possible video chat

Reduced Costs/Aversions for <i>Beneficiaries</i>	Potential <i>artefact</i> Features
Reduce/remove time taken to travel for <i>care circle members</i> for meetings	Synchronous and asynchronous usage

Easier to arrange meetings between <i>care circle members</i>	Sharing calendars
---------------------------------------------------------------	-------------------

4.5. Chapter 6 - Assumptions to be Confirmed and Incomplete or Missing Information from Findings

The [Worth Shift Tables \(Section 4.3\)](#) and the [Artefact Connection Tables \(Section 4.4\)](#) were examined to identify assumptions and any gaps in information that may help confirm them. Alphanumeric characters were assigned to each one of them.

Incomplete or Missing information
A. What is good about the current situation
B. List of what is not ideal about the current information

Assumptions to be Confirmed	Confirm by Gathering Information on (letters refer to Table 6.7)
1. There is a need for frequent communication within care circles	D
2. That social networking is a viable solution	A, E, F

The questionnaire in Chapter 6 was developed with reference to each of these items recognised in these tables.

5. Glossary

This glossary lists and defines terms that are repeatedly used throughout the thesis.

- Words in *italics* can be cross references within the glossary.
- Terms marked with a * are new terms introduced in this thesis.
- For terms that are debated with multiple definitions, the interpretation used in this thesis is provided.
- The Section references in the definitions are to the thesis.

Term	Acronym (if used)	Definition
Abstract Design Situation	ADS	When a <i>CDS</i> is simplified to a set of <i>design arenas</i> and their inter-/intra connections. (Cockton, 2010; See Section 2.2.2.4)
Adumbrative function		A function that can roughly outline a <i>design chunk's</i> scope as an ADS at some level of abstraction (e.g., <i>MADS</i> , <i>design arena progress</i>) (Cockton, 2013b, p.13; See Section 2.3).
Ameliorative function		A function that can communicate a <i>design chunk's</i> guiding values (Cockton, 2013b, p.13; See Section 2.3).
Artefact		A <i>design arena</i> comprising options and choices for the form, features, capabilities and qualities of a material and/or intangible object (Cockton, 2010, See Section 2.2).
Artefact Connection Table*		A table used to link <i>artefact</i> features with <i>worth</i> . i.e. increasing benefits and reducing adverse outcomes (Section 6.3.2; This document Section 4.4).
Assistive Technology	AT	Technology used to support individuals with disabilities (LaPlane <i>et al.</i> , 1992; See Section 3.4).
Balanced, Integrative, Generous Design Process	BIG Design Process	A <i>design process</i> that balances <i>design arenas</i> and integrates between and within them), where choices of design (<i>purpose</i>) are generous (Cockton, 2010; See Section 2.2.2.4)
Beneficiaries		A <i>design arena</i> comprising who we are designing for and what matters about them (Cockton, 2010, See Section 2.2).

Term	Acronym (if used)	Definition
Comprehensive Assistive Technology Model	CAT Model	An application of the <i>ICF model</i> for identifying, evaluating, supporting ATs (Hersh & Johnson, 2003; See Section 3.2.5)
Concrete Design Setting	CDS	Current state of design process across <i>design arenas</i> including any available design chunks (Cockton, 2010; See Section 2.2.2.4).
Decision Support System	DSS	DSS is an umbrella term used to describe a computerised system that supports decision-making (Turban <i>et al.</i> , 2005; See Section 4.2).
Design Approach		A collection of incomplete resources and incomplete implementation process that has been planned (Woolrych, <i>et al.</i> , 2001)
Design Arena		Options associated with a single type of <i>design choice</i> . Design arenas for this research are: <i>Beneficiaries, Evaluations, Artefact, Purpose</i> (Cockton, 2010, See Section 2.2).
Design Arena Progress* List	DAP List	The most concrete abstraction of <i>ADS</i> where findings are identified against each <i>design arena</i> .
Design Chunk*		A coherent extent within design practice ranging from the most abstract (<i>design paradigm</i>), through <i>design process</i> , <i>process stage</i> and <i>design approach</i> , to the most concrete (<i>design resource</i>).
Design Move		A change within one or more <i>design arenas</i> .
Design Paradigm		The most abstract form of <i>design chunk</i> , i.e, the design milieu for a design process.
Design Process		A structure for <i>design work</i> made up of stages.
Design Resource		Tools used within a <i>design process</i> (often within <i>design approaches</i>)
Design Work		Raw empirical information produced prior to analysis. In the case of this thesis, activity records.
Directive function		A <i>design chunk's</i> function that systematically guides <i>design work</i> (Cockton, 2013b, p.13; See Section 2.3).

Term	Acronym (if used)	Definition
Evaluations		A <i>design arena</i> comprising options for and outcomes of assessment of a <i>CDS</i> (and thus can include evaluations of evaluations) (Cockton, 2010, See Section 2.2).
Expressive function		A <i>resource</i> function that records (evidence for) options within a design arena (Cockton, 2013b, p.13; See Section 2.3).
Informative function		A <i>resource</i> function that informs <i>design work</i> (Cockton, 2013b, p.13; See Section 2.3).
Inquisitive function		A <i>resource</i> function that provides questions for <i>design work</i> (Cockton, 2013b; See Section 2.3, p.13).
Integrative function		A <i>resource</i> function that connects across and/or within <i>design arenas</i> (Cockton, 2013b, p.13; See Section 2.3).
International Classification of Function, Disability and Health Model	ICF Model	A holistic model of disability as defined by the World Health Organisation (WHO) that is more than biomedical.
Invigorative function		A <i>design chunk's</i> function that energises and strongly motivates <i>design work</i> (Cockton, 2013b, p.13; See Section 2.3).
Iteration Shift*		Where the design move of each <i>design arena</i> is recorded, typically expressed as a table with one row per design arena (This document Section 3.5).
Most Abstract Design Situation*	MADS	The highest level of abstraction of <i>ADS</i> where only the existence of a <i>design arena</i> or connection is indicated (This document Section 3.3).
Performative function		A <i>resource</i> function that persuasively communicates (parts of) <i>design arenas</i> to an audience (Cockton, 2013b, p.13; See Section 2.3).
Process stage		Part of a <i>design process</i> and an episode of <i>design work</i> . e.g., Requirement specification, evaluation.
Proportional Abstract Design Situation*	PADS	The second level of abstraction next to <i>MADS</i> that shows the extent of anticipated or actual <i>design arena</i> findings (This document Section 3.4).

Term	Acronym (if used)	Definition
Protective function		A <i>design chunk</i> 's function that detects and removes risks from design work (Cockton, 2013b, p.13; See Section 2.3).
Purpose		A <i>design arena</i> comprising the goals for a design (Cockton, 2010, See Section 2.2).
Reflection <i>in</i> Action		Reflection in Action is when "practitioners are able to describe how they 'think on their feet', and how they make use of a repertoire of images, metaphors and theories" (Smith, 2001)
Reflection <i>on</i> Action		Reflection on Action is when "people draw upon the processes, experiences and understandings generated" (Smith, 2001)
Research <i>for</i> Design		Research for design is when original reusable design resources are produced by research (See Section 2.1.3.2).
Research <i>into</i> Design		Research <i>into</i> design is the study of design. The most common are: historical Research, Aesthetic or perceptual research; research into a variety of theoretical perspectives and PhD or MPhil dissertations (Frayling, 1994; See Section 2.1.3.2)
Research <i>through</i> Design Process	RtD	A research approach that uses design work as an essential methodological component. Eg. materials research, development work, action research. (Frayling, 1994). Knowledge is the main outcome rather than just a successful artefact (Section 2.1.3.2).
Resource Function Analysis	RFA	Analysis of any <i>design resource</i> use within design work to identify the nature of the work is achieved. The Resource Function vocabulary from Cockton's Working to Choose Framework is used in this thesis, i.e.: <i>adumbrative, ameliorative, inquisitive, directive, expressive, informative, performative, invigorative, protective and integrative</i> (Cockton, 2013b, p.13; See Section 2.3)

Term	Acronym (if used)	Definition
Total Iteration Potential	TIP	The ability to realise any <i>iteration shift</i> during any <i>stage</i> , through a lack of constraints on <i>design moves</i> within an iteration (Cockton, 2006; See Section 2.2.2.4).
Value-Centred Development	VCD	A four step design process with limited parallel activities that focuses on worth as a basis for integrating design arenas (Section 2.2.1.3).
Working to Choose Framework	W2C	A framework that combines the concepts of ADS, meta-principles and RFA to support reflection on past, current and future design work and support for it (Cockton, 2013a, p.1; See Section 2.3).
Worth		A balance of value over costs and risks (Cockton, 2008a; See Section 2.2.1.4).
Worth Integration Table*		A table that associates <i>artefact</i> features with <i>purpose</i> elements (improved benefits and reduced costs/ adverse effects/aversions in a worth-focused approach) (See Sections 4.8 and 5.6 and this document Section 4.2)
Worth Shift Table*		A table that records current and ideal or preferred state for beneficiaries (See Section 6.2; This document Section 4.3)
Worth-Focused Design Approaches	WFD	<i>Design Approaches</i> that advance a purpose <i>design arena</i> and connections to it by focusing on worth.

**Fast-Track form, for project ethical approval.
Mic Porter, originated – September 2009.
Kev Hilton, revised – March 2010.**

Introduction

It is apparent that much of the work undertaken, especially by those on taught programmes is routine and thus suitable for evaluation via this Fast-Track form. Furthermore, our style of, often short-time-scale, project based teaching makes a more formal and detailed approval process for all projects unwieldy and unsuitable. Therefore the Fast Track form functions as a checklist and proposal form to provide quick review and guidance as to whether there may be a dilemma which needs bringing to the DSEC's attention for recommendations. If a dilemma or potential dilemma is identified it will require the completion of the Ethical Dilemma form available on the public folders, under School of Design / Committees / Ethics.

Do I need to seek approval from the DSEC?

The proposed flowchart for the resolution of this initial question can be found in Appendix 1.

In the first instance, the "Fast-Track" (FT) approach should be considered and only, if directed by the form, should an Ethical Dilemma form be submitted. In the case of students on taught programmes who are undertaking Briefs devised for educational objective it should be sufficient for the Module Tutor to consider the ethical issues and to submit one FT Form for the whole group. In the case of the Module Tutor also being the Programme Leader, if the latter has any doubts or concerns they should forward the completed form to the Chair of the DSEC for advice. It is envisaged that this will be the common and appropriate mode for work at Levels 4 and 5 and some level 6 or 7 work.

In the case of major projects (generally level 6 & 7) it is expected that the student will complete the form (and to regard this as part of their training for professional practise) and, in most cases, for the Programme Leader (or nominee) should feel able to approve the proposal. However, if any doubt exists then the responsibility must reside with the DSEC to whom the application must be forwarded promptly. Given the limited size of teaching teams it is assumed that the Programme Leader would refer any doubt, dilemma or "problematic" FT request upwards to the DSEC; possibly via those staff who lead subject and/or research grouping. It is, however, important that the path between Applicant, Programme Leader and DSEC, where the ultimate responsibility lies, is clearly defined and monitored.

A summary of decisions made by the Programme Leaders must be given to the DSEC who might, among other options, use the material as examples from which to set precedent and to create cases for staff training. The DSEC will retain all FT applications until such time that they are completed and cease to be relevant.

Timescales and Process

In the case of FT applications this matter is left to the Programme Leader/nominee but a summary of the approvals and referrals made should be submitted to the DSEC according to a schedule corresponding to the formal meetings of the committee. I would expect the DSEC to note and record the summary and, if necessary, review and offer guidance to the appropriate staff.

In the case of more substantial or “problematic” applications I believe the DSEC should seek to resolve matters quickly and thus minimise the impact upon the project and the work of the School. Thus:

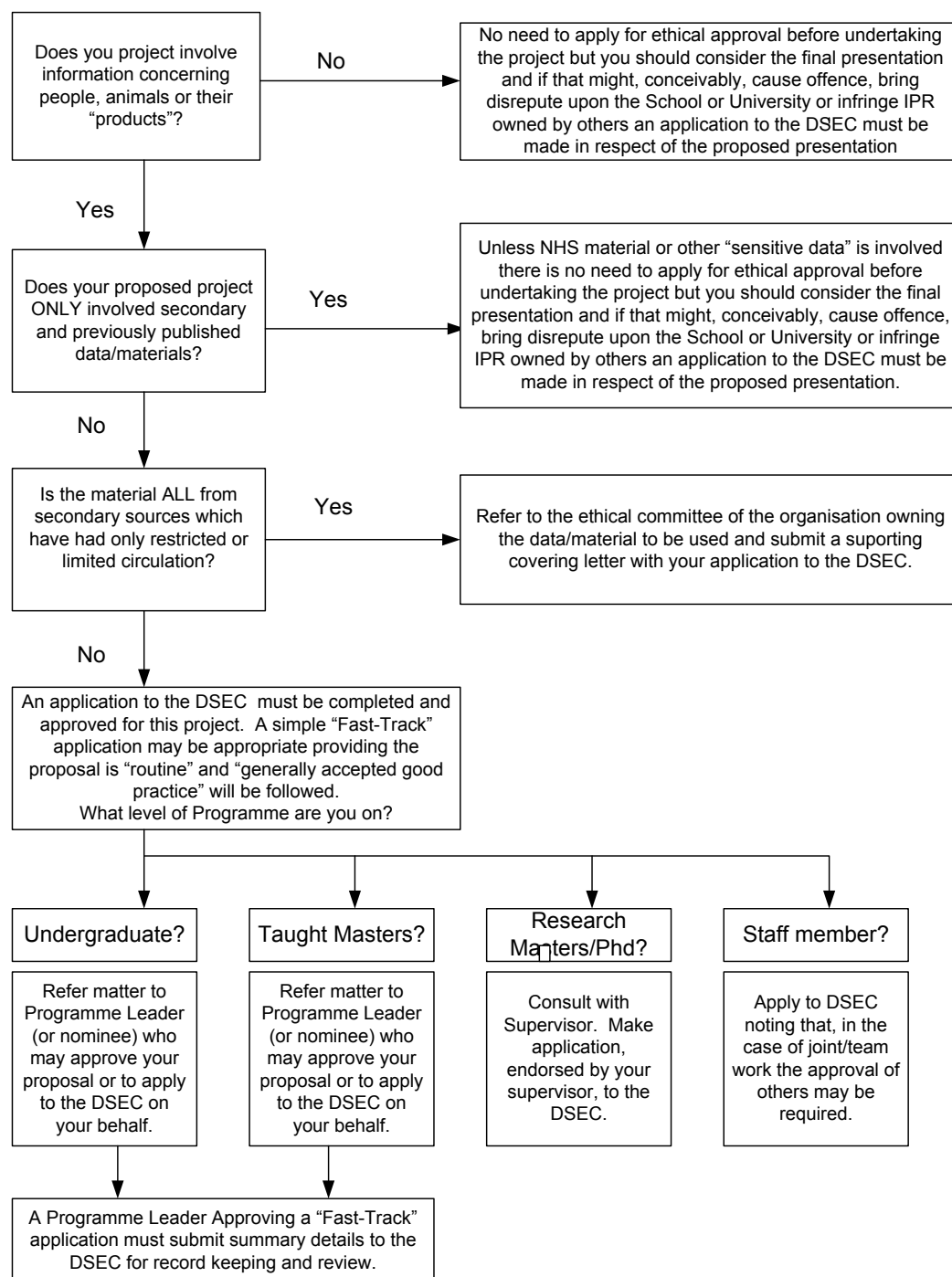
1. Full application forms should be checked for completeness upon submission and, in “term-time”, circulated fortnightly to the members of the Committee requesting automatic acceptance, comments and observations with the next fortnight. This should also be the case for “problematic” FT forms that have been referred to the DSEC.
2. Any proposal not receiving unanimous acceptance to be placed on the Agenda for the next DSEC meeting but feedback given to the applicant who would be encouraged to propose modifications in the light of the comments/observations. In case of “minor” issues the DSEC Chair may seek resolution and report back to the next full committee meeting.
3. The dates of the DSEC meetings will be set at intervals that permit a timely response to the applicant and noting that meetings without completed content that can be circulated ten days in advance be cancelled. Monthly during “term-time” would seem appropriate – perhaps the second Wednesday of September, October, November, December, January, February, March, May, June and July. The dates of these meeting to be published annually.
4. In the case of applications from committee members they should withdraw while their matter is considered and, if necessary, an alternate Chair appointed.
5. However, it has been found by the Association of Research Ethics Committees that it can be helpful to invite project leads to be present at review to answer questions and inform a more timely approval, so the DSEC may choose to invite applicants to be present.
6. The outcome of the application should be conveyed promptly to the applicant (and Programme Leader/Supervisors). In the case of an unsuccessful application an offer of feedback/guidance from a nominated member of the DSEC should be given.

This process is outlined in Appendix 3.

Appendix 1.

Do I need to seek approval from the DSEC? A proposed flowchart.

Do I need to seek approval from the Design School's Ethical Committee (DSEC)?



Draft – version 1.0
September 2009

Appendix 2.

Fast-track ethical approval form School of Design

Applicant: Contact details: Jennifer George
Programme Leader/Supervisor details: Prof. Gilbert Cockton
Project Title: BEYOND BODIES: SITUATING ASSISTIVE TECHNOLOGY FOR YOUNG CHILDREN WITHIN WORTHWHILE SOCIO-DIGITAL SYSTEMS
Date application made:

DSEC Use Date application received:	Date response made:
Outcome: Approved/Approved with conditions/referred to DSEC/full Approval Form required/rejected (circle, date, initial & status (PL/Chair DSEC/etc))	

If you are unclear about any ethical issue that might arise from your proposed project you must seek guidance from your Programme Leader (or nominee)/Supervisor and/or the Chair of the DSEC. For each question please tick the appropriate box.

		Yes	No	N/A
1	Will you only recruit participants that are not known to you, e.g. by email or other networking system (eg "Facebook" & "Myspace")?		X	
2	Will you describe the main procedures to participants in advance, so that they are informed about what to expect?	X		
3	Will you tell participants that their participation is voluntary?	X		
4	Will you obtain written consent for participation and, if relevant, the use of images/recordings in presentations and for public display?	X		
5	Before any data is collected will you tell participants that they may withdraw from the project/research at any time, for any reason and that they need not give you any details beyond their withdrawal?	X		
6	Will you identify yourself, the level of your study and provide your participants with your contact details in a form that they can retain?	X		
7	If the research is observational, will you ask participants for their consent to being observed/recorded?			X
8	If you intend to record the image and/or voice of any of the participants, will you ask for their consent?			X
9	With questionnaires and interviews, will you give participants the option of omitting questions they do not want to answer?	X		
10	Will you tell participants that their data (including images and other recordings) will be treated confidentiality and that, if published/used in a public presentation, the data will not be identifiable?	X		
11	Will you tell participants how and when their data will be disposed after the project has been completed or if they choose to withdraw?	X		
12	Will you give participants the opportunity to be debriefed and/or invited to any public presentation of the study and its outcomes/results?	X		

If you have answered **No** to any of questions 1 –12 you should complete and submit in full the DSEC Ethical Dilemma Form.

		Yes	No	N/A
13	Will your project deliberately mislead participants in any way?		X	
14	Is there any realistic/conceivable risk of any participants experiencing either physical or psychological distress or discomfort?		X	
15	Is the nature of the research such others might believe that any legal, contentious or sensitive issues are involved or are to be presented?		X	

If you have answered **Yes** to any of questions 13, 14 or 15 you should complete and submit in full the DSEC Ethical Dilemma Form. In relation to question 13 this should include details of what you will tell participants to do if they should experience any problems (e.g. who they can contact for help). You may also need to consider Health and Safety and other risk assessment issues.

		Yes	No	N/A
16	Does your project involve work with animals: fish, birds, etc (wild or domesticated)?		X	
17	Will any part of the data collection or the presentation of outcomes occur outside of the UK?	X		
18	Do any of your participants fall into any of the following “special” (aka “vulnerable” groups)? <ul style="list-style-type: none"> • Children (under the age of 18) • People who are patients or seeking medical treatment • People who are frail or with communication or learning difficulties (includes “the elderly” and people from overseas for whom English is not their primary language) • People engaged in illegal activities (eg under aged drinking or drug taking) • People undertaking activities that might be seen as provocative or morally unacceptable (eg promoting disruptive or anarchic activities) • People over whom you are in a position of superior power or for whom you have responsibility • People whom others could regard as vulnerable or who might feel that they are unable to, freely, give consent 		X	
19	Does the proposal involve a show, exhibition, etc which will be open to people from outside the Design School (potential students, general public and reporting Media, etc) who may, conceivably, regard the artefact and/or the presentation of it as illegal, in breach of any IPR held by others or morally unacceptable?		X	
20	Does the project involve external funding (financial or “in-kind”) or collaboration with others outside the School of Design (eg elsewhere in the University or beyond, and, particularly including the NHS)?			X
21	Does the project require the School/University to provide evidence of your status or that the project has passed the ethical scrutiny of the DSEC?		X	

If you have answered **Yes** to either question 16 – 21 you should complete in full the DSEC Ethical Dilemma Form. If you have answered **Yes** to question 18 you may require a “Criminal Records Bureau (“CRB”) clearance prior to undertaking the work. This should be discussed with your tutor/supervisor immediately.

Before approval is granted you may be asked to submit supporting documentary evidence (instructions to participants, form to be signed approving the use of images, etc). You may also be asked for clarification for your answers (work involving the eradication of urban rats or slugs, for example, may be viewed from different perspectives). It may be beneficial to your application if you include such supporting materials with the application.

In submitting this form, you accept the obligation upon you to bring to the attention of the DSEC (or nominee) any issues with ethical implications that may not be covered by these twenty-one questions. Furthermore, if circumstances change you must bring the details to the immediate attention of the DSEC.

If the DSEC becomes aware of any problematic issues associated with this application approval may, immediately, be revoked or conditions attached to the work.

Please give a brief description of your proposed project, participants, approach/methods and intended outcomes/presentations/publications.

Children with motor impairment use assistive devices to communicate with members of their care circle at home, school, play group, hospitals, care environments and also other public places. However, many of these assistive devices either end up being in the cupboard or are used to communicate with only some members of the care circle. Not knowing how to use the device; unwillingness of members of the care circle in using the devices with the children; unresolved technical problems; device not meeting the purpose and not knowing how to use them are some of the reasons why these devices are abandoned.

A questionnaire has been used to collect data on Costs, benefits, values and worth in the requirements of the members of the care circle are identified. Their demographics were also recorded. Participants were family members of motor impaired individuals and professionals involved in their communication and development. The collected data has been analysed to develop a social network that will be used by members of the care circle.

The research aims to improve the capability of children with motor impairment by the development of a worthwhile socio-digital system, a social network. The social network will attempt to address the challenges in physical networking within and between care circles; and improve the current communication methods at their disposal. This social network also will support members of the family and professionals involved in the care of the child in providing a range of information to support them with the care of their child; information in choice and use of assistive devices; communicate with other care circles; share thoughts, events and news items, and work towards enhancing the capability of their children.

Specifically, participants will be members of the care circles of children with major motor impairments (e.g., due to Cerebral Palsy, typically preventing the development of normal speech). The children themselves will not be participants in the research. Care circle members will use a custom social network platform for mutual support over a period of a few months. Further questionnaires will be administered via the social network platform, and visits will be made to care circle members, who will be interviewed about their experiences, with some usage observed during the visits.

Two ethical issues arise.

Question1:

Firstly, several of the members of care circles, including parents, are already known to the researcher from previous research. To avoid undue pressure to support the researcher here, these participants will be expressly briefed prior to signing an informed consent form with the objective of ensuring that they are free to not participate and to withdraw at any time, without adverse consequences on existing relationships.

Question 17:

Secondly, some data will be collected in Sri Lanka. Data protection and privacy laws are as in the UK,

so no additional requirements arise here relative to UK participants, where all rights will be fully observed. A consent form will be used for data collection and usage.

I consider that this proposal has no significant ethical implications requiring the DSEC Ethical Dilemma form to be completed and submitted. I will not proceed with this project until Approval has been obtained from the DSEC or Programme Leader.

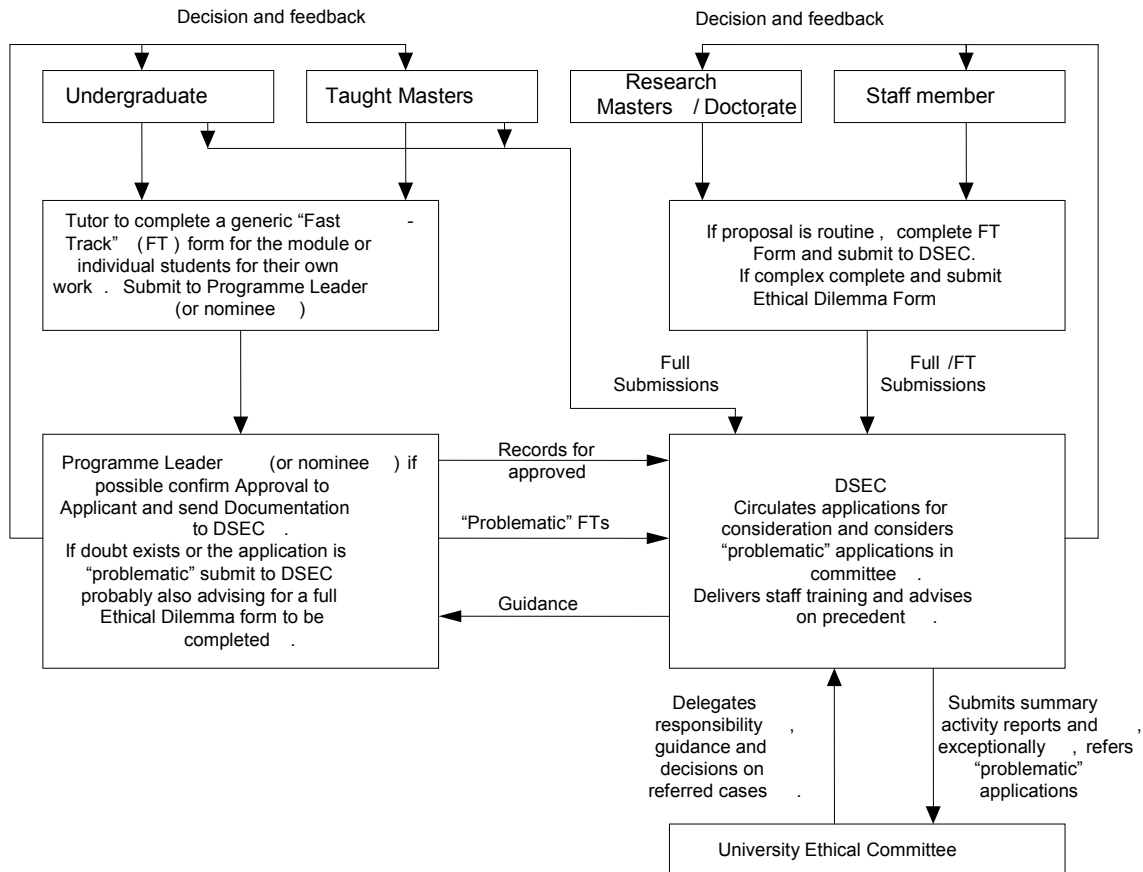
Signed and dated by the applicant:

Countersigned (confirming details)
Tutor/Programme Leader (or nominee)/Supervisor:

Appendix 3.

A flowchart for the proposed process

DSEC Process Flow Chart



Consent form

The research aims to improve the capability of young children with motor impairment by the development of a social network that can overcome difficulties associated with face to face contact. The social network will enable support within and between care circles by improving the current communication options at their disposal. This social network also will support members of the family and professionals involved in the care of the child in providing a range of information to support them with the care of their child: information in choice and use of assistive devices; communicate with other care circles; thoughts, events and news items; and other useful sources of support and information. This will provide better support care circles to work towards enhancing children's capabilities.

Purpose: This study is conducted to identify if the social network improves the existing support and solutions you have with regard to the individual(s) you care for.

I am a PhD student in Northumbria University and if you have any queries, you may contact me, Jennifer George on 079 3080 1010 or jenni26cg@gmail.com.

Your time and effort is truly appreciated.

What are you being asked to do?

- You will be asked to use a web-based social network for a set period of time as much as you think appropriate. Tasks you may complete:
 - Invite others as you think fit. This could include, other parents, your immediate and extended family members; colleagues; medical practitioners; educationalists;
 - Ask questions from those you have added to the circle;
 - Use and share the information in the website;
 - Find information and make requests for information you cannot find;
- After a month of usage, you will be asked to complete a questionnaire.

Your Rights

- Participation in this study is voluntary.
- All information will remain strictly confidential. The descriptions and findings may be used to help improve the social network. However, at no time will your name or any other identification be used.
- The data collected in this study may be used in research publications, but anonymised.
- You can omit any questions you may wish not to answer.
- You can withdraw your consent to the experiment and stop participation at any time.

I have read and understood the information on this form.

Participant' Signature

Date

Researcher's Signature

Date



Jennifer George <jenni26cg@gmail.com>

Ethics document and Consent Form

1 message

Jennifer George <jenni26cg@gmail.com>

13 March 2012 at 01:00

To: "Gilbert Cockton (Northumbria)" <gilbert.cockton@northumbria.ac.uk>

Dear Gilbert,

Further to our discussion on updating the Ethics and Consent form, I have revisited the documents submitted in March 2011 and confirm that they are still applicable.

However, I have noticed an inconsistency between the ethics document and the consent form where in the ethics document I have stated participant observations as not applicable while the Consent Form includes observations. The Consent Form is correct and this is what I have been using for the evaluation of the website.

I have attached herewith the amended version of the Ethics document and the Consent form that remains unchanged.

Regards,

Jenni

2 attachments



ConsentForm 090511.doc

32K



Fasttrack Ethical Approval Form_120312.doc

120K

Ethical Approval Form v6

School of Design, Northumbria University

Applicant: Jennifer George

Contact details: jenni26cg@gmail.com

Programme Leader/Supervisor details: Gilbert Cockton, (gilbert.cockton@northumbria.ac.uk);
(second supervisor and deputy: Thomas Greenough (Thomas.Greenough@northumbria.ac.uk))

Project Title:

**BEYOND BODIES: SITUATING ASSISTIVE TECHNOLOGY FOR YOUNG CHILDREN
WITHIN WORTHWHILE SOCIO-DIGITAL SYSTEMS**

This ethical approval form addresses the need for an online system that combines social networking capabilities, which is an outcome of this study being evaluated by participants. This is further described in this form.

Date application made: 22/10/2012

Through completing this form, you *either* indicate that all identified ethical issues can be managed without guidance from DSEC, *or* that DSEC advice is required. If you are unclear about any ethical issue that could arise from your proposed project, you must seek guidance from your Programme Leader (or nominee)/PGR Supervisor/Research Grouping Lead/ DSEC member. You must *not proceed* with any research until required approval has been obtained from your Programme Leader (UGs/PGTs)/Principal Supervisor (PGRs)/DSEC (staff/other research requiring DSEC advice).

You must complete both Section A and B, and with this form you must submit all required supporting materials, for example, Informed Consent form(s). For each question in Section A please tick the appropriate box.

SECTION A.

You *will* complete and submit the School's Standard Informed Consent form, which will make clear to participants their Right to Withdraw, and Confidentiality of information.

		Yes	No	N/A
1	RECRUITING. When recruiting participants known to you could there be concerns over your power relationship that may influence their responses?		X	
2	DECEPTION. Will you deliberately deceive participants, and hide this deception from them?		X	
3	DISTRESS OR DISCOMFORT. Is there any realistic/conceivable risk of any participants experiencing either physical or psychological distress or discomfort?		X	
4	ANIMALS. Does your research involve animals?		X	

Only in exceptional circumstances will you be permitted to use deception in your research. If you have answered **Yes** to Questions 1-4 you must describe how you will address associated ethical issues in SECTION B.

		Yes	No	N/A
5	DEBRIEFING. Will you give participants the opportunity to be debriefed and/or invited to any public presentation of the study and its outcomes/results?	X		
6	INTERNATIONAL. Where data collection or presentation of outcomes occurs	X		

	outside of the UK, are relevant legal and ethical practices of these other countries understood?			
--	--------------------------------------------------------------------------------------------------	--	--	--

If you have answered **No** to Question 5 or 6 you must describe how you will address associated ethical issues in SECTION B.

7	VULNERABILITY. Do any of your participants fall into any of the following “special” aka “vulnerable” groups? <ul style="list-style-type: none"> • Children (under the age of 18) • People who are taking part in your research because they are patients or seeking specific medical treatment • People who are frail or with communication or learning difficulties (includes “the elderly” and people from overseas for whom English is not their primary language) • People part in your research because they engage in illegal activities (e.g. under aged drinking or drug taking) • People undertaking activities that might be seen as provocative or morally unacceptable (e.g. promoting disruptive or anarchic activities) • People over whom you are in a position of superior power or for whom you have responsibility • People whom others could regard as vulnerable or who might feel that they are unable to, freely, give consent 		X	
8	LEGALITY. Might others believe there to be any legal, contentious or sensitive issues involved in this research method or in presentation of the research outcomes?		X	
9	FUNDING. Does the project involve external funders (financial or “in-kind”) or collaboration with others outside the School of Design (e.g. elsewhere in the University or beyond, and, particularly including the NHS), who may wish to direct your research?		X	

If you have answered **Yes** to any of Questions 7-9 you will must describe how you will address associated ethical issues in SECTION B.

*If you have answered **Yes** to Questions 7 or 8, DSEC approval may take longer, especially if proof of UK CRB clearance or similar is required.*

SECTION B.

List all attachments here, (e.g. questionnaire designs, interview schedules, observation plans)

All of the following guidance text must be deleted and replaced with information relevant to specific ethical issues. For every ethical issue identified in Section A, you must describe how you will deal with these. Advice on common risk mitigation strategies follow. Please reflect carefully before making direct use of any text below. It is much better to explain risk mitigation in your own words:

Background of project:

Children with motor impairment use assistive devices to communicate with members of their care circle at home, school, play group, hospitals, care environments and also other public places. However, many of these assistive devices either end up being in the cupboard or are used to communicate with only some members of the care circle. Not knowing how to use the device; unwillingness of members of the care circle in using the devices with the children; unresolved technical problems; device not meeting the purpose and not knowing how to use them - these are some of the reasons why these devices are abandoned.

First ethical approval in March 2011 addressed the following needs: A questionnaire was

used to collect data on Costs, benefits, values and worth in the requirements of the members of the care circle. Their demographics were also recorded. Participants were family members of motor impaired individuals and professionals involved in their communication and development. The primary challenge was identified as communication between members of care circles.

The collected data was analysed to develop an online system that incorporated social networking capabilities. Professionals and parents evaluated the first version of the online system for usability and scope. Based on their feedback, the second version of the website has now been created.

Ethical approval now requires to be extended to the following for an evaluation of an online support system:

1. Overview of System

What is the system?

The research aims to improve the capability of children with motor impairment by the development of an online system that combines social networking capabilities. This system has been custom designed based on findings of the research. Access to the system is password protected, with accounts restricted to invited members of care circles.

What does the system do?

The online system will attempt to address the challenges in physical networking within and between care circles; and improve the current communication methods at their disposal. This system also will support members of the family and professionals involved in the care of the child in providing a range of information to support them with the care of their child; information in choice and use of assistive devices; communicate with other care circles; share thoughts, events and news items, and work towards enhancing the capability of their children.

What does the system not do?

The system is not used by the disabled individuals and the support provided via this network does not replace existing assessment or face-to face communication.

2. Who will use it?

Participants would be those similar to those of previous study. More specifically, they will be members of the care circles of children with various disabilities. The children themselves will not be participants in the research.

While the study evaluates support for vulnerable individuals, none will directly participate in

the study. The participants will be the legal guardians and other consenting adults who may be immediate and extended family members, teachers and education practitioners, doctors, therapists and medical practitioners, anyone else the legal guardian authorises.

Participants will be recruited from personal contacts, including those who contributed to earlier questionnaire and those professionally recommended by Dr. Mary Akinola, a GP in Oxford, who has been an evaluator in every step of the research.

3. What Participants will do with the system, requested tasks and free use

Pre-populating data: Ahead of usage, collaborating with GP, the system will be pre-populated with resources. This will include general information on:

- Assessments
- Assistive Technology
- Care and Hygiene
- Education
- Entertainment
- Funding Assistance
- Psychological Needs
- Support for Carers
- Therapy
- Technical Support for AT

Using this web platform, users can:

- Effectively communication via private messages, restricted and public forums and video chats
- Provide continuous support thereby reducing expensive assessment
- Create and keep track of events
- Share information

Participants will use the system for a period of three months. They may start using the website immediately. However, during this period, they will be specifically asked to complete the following tasks and interactions.

Registration and consent: Each user will join the system mycarecircle.com by way of registration. As part of this process, they will accept the terms and conditions and provide consent to the evaluation research. Upon the user's acceptance, the user will receive email from the researcher, containing the text of the online consent, and they will be asked to confirm receipt.

Now that the user has been registered and has consented to the study, he/she will

complete the following tasks:

Task 1: Legal guardian creates profile for child. This will include: description of special needs, AT devices, environments where support is required. This is viewed only by those invited by the legal guardian.

Task 2: Legal guardian invites members and creates care circle. Access to the system is restricted to participants in the study and those care circle members who have accepted their invitation to participate. For observation purposes, the researcher also needs to be invited to join the care circle. The research will be a silent observer and will not participate in communication except for initiating tasks via messages within the care circle using the website.

Task 3: Posts a question about supporting the child and responds to two questions posted by others (question may be about education, assistive technology or communication)

Task 4: Looks at available information; requests further information or shares additional information

Task 5: Share any interesting activities or progress of child with care circle

Task 6: Have a video conversation or send a personal message relating to progress of your child with any or few members of your care circle.

At the end of the three months of further unguided use, a questionnaire will be used to respond to any questions arising from the study, relating to the set tasks and any additional activities. As this is dependent upon the results of the current study, this will be addressed by way of a separate ethical application.

4. What data will be collected?

Observations by way of being a member of care circle will enable study of:

- engagement frequency;
- nature of engagement;

Data from the message content will be used to identify:

- purpose of communication;
- engagement;
- problem solving potential.

Google analytics will be used to identify:

- the type of device used to access the website, whether mobile or fixed;
- location from where the website is accessed;

5 How this data will stay secure

The developer has administrator access for development of the website and data. The researcher has administrator access to verify details of registered users. However, the researcher cannot join a care circle without authorisation of the legal guardian.

There is a 12 months maintenance agreement between the developer and the researcher. The Developer will only access a minimal set of personal data if participants report a technical problem to the researcher (access depends on the problem). This is mentioned in the consent form.

6 Storage and Disposal of data

Online data will be stored for as long as the website is active. Participants have rights to remove data or close their account at any time after signing up. Other digital notes or copies made to evaluate the data will be kept in a password protected personal laptop until the end of the PhD and any relevant publications and thereafter destroyed after no later than 3 years.

7. Summary of potential ethical issues and responses:

1. **Recruiting:** Participants are those who have been part of previous evaluations and have shown interest in the system. Participants will not be pressured into participating and they will be informed explicitly of their right to withdraw during the recruitment process, and confirm their understanding of this in the consent form.
2. **Debriefing:** At the end of the three months, participants will be invited to a video chat using the system or individual chats for debriefing. There will be an opportunity to provide further feedback in a questionnaire that will be designed towards the end of the three month period. Participants will be provided with an opportunity to see the results arising from evaluations prior to any publication.
3. **Deception:** Deception will not be used as part of the study under any circumstances.
4. **Distress or Discomfort:** General guidance will be provided to initiate activities. The information provided and tasks initiated will be of the participant's own choosing. Participants who do experience difficulties will be reminded of their right to leave the study at any time and remove any information they provide at anytime.

5. **International:** One care circle has shown interest in Sri Lanka. Sri Lanka has privacy legislation similar to the United Kingdom but in practice is more lenient than the UK as subject of disability support is relatively new. Throughout the study, more demanding UK standards of privacy will be adhered to.
6. **Vulnerability:** While the study is focused on supporting vulnerable individuals, only legal guardians and consenting adults by invitation of legal guardians to vulnerable individuals is required.

The researcher is a volunteer counsellor at ChildLine (NSPCC) and can provide copy of CRB report.

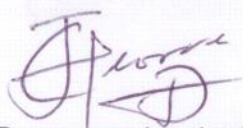
7. **Legality:** Data collected will not be used for any purpose other than described in this document and the consent form. While it is hoped that the system will continue to be active and grow, participants have right to leave the study and the system at any time, and can delete or edit information that they have added, and can close their account. Results arising from evaluation will be destroyed no later than 3 years after the end of the PhD and any resulting publications. Data will not be shared with anyone not prescribed in this document under any circumstances.
8. **Funding:** No funding is required, so the researcher's independence cannot be compromised.

In submitting this form, you accept the obligation upon you to bring to the attention of the DSEC (or nominee) any ethical issues that may not be covered by the above questions.

If ethically relevant circumstances of your research change, you must bring this to the immediate attention of the responsible party (Programme Leader/Supervisor/ACoP Research Lead/DSEC). For major changes of research plan or implementation, you must submit a new application for ethical approval. If the DSEC becomes aware of any problematic issues associated with your project, approval may be immediately revoked, with conditions imposed that must be met before new approval will be given.

I, the researcher/designer, have fully described in Section B how I will manage all ethical risks highlighted in Section A, and have sought DSEC advice and approval for all significant ethical implications. I will *not proceed* with this project until approval has been obtained from DSEC/Programme Leader (UGs/PGTs)/Principal Supervisor (PGRs).

Signed and dated by the applicant: ~~30/05/2012~~



2/11/2012

Programme Leader (or nominee)/Supervisor - countersigned and dated to confirm all details above and approval of research:



2/11/12

For DSEC Use where application requires DSEC advice and approval

Date application received:

Date response made:

Outcome:

Approved / Approved with Conditions / Referred to UREC / Returned for Revision

(circle, date, initial & status (PL/Chair DSEC/etc))

C3 - Assistive Technology (AT)

A major strategy to reducing disability is the provision of Assistive Technology (AT). AT is a generic term used for solutions that assist people with deficits in physical, mental or emotional functioning. They may be low-tech or high tech and enable users to perform tasks, actions and activities in alternative ways (LaPlante, *et.al.*, 1992).

Able-bodied users are able to adapt to many different devices comfortably. However disabled users, especially children with severe motor impairment, need to reduce their disabilities by adjusting to different input and output, ergonomic designs and environment designs each time they use a different AT to communicate.

The constant use of arm, wrist and fingers are necessary to have complete control over both low-tech and high-tech devices. To a motion-impaired user, gaining complete control over control devices can be challenging. AT for people with motor disabilities either work through the keyboard and mouse or emulate the functionality of the keyboard and mouse (WebAim, 2007). Special handles or grips may become necessary to hold small objects. Special bends, curves, handles and grips may also be necessary to improve motor skills (Zisook, 2007). Participants with physical impairment also use a variety of mobility aids, for example mobile keyboards, alternative mice and monitor arms (SpecialNeeds Computer Solutions, 2007), walkers, motor wheelchairs, electric wheelchairs (ABLEDATA, 2007). The device used and the usability depends on the experience of the user (Jordan, 1998).

The use of AT devices could be made to suit the user further by making software based changes or hardware modifications. When there is no control over the arm, alternative communication methods based on other modalities such as speech, head and brain-controlled interfaces could also be made available.

Ubiquitous or pervasive computing is brought about by the convergence of media and the physical environment making interactivity more natural and more seamless. Touch and gestural interfaces such as Apple's iPhone, iTouch, iPad, Microsoft Surface and Nintendo's Wii incorporate a variety of input, output, data, connectivity and interoperability. Surface, a tabletop interface, enables grabbing and moving data using natural touch and gestures (Microsoft, 2008). Touch-based e-book readers,

including their accessible versions, provide further opportunity for users with motor impairment.

Many ergonomic and assistive devices are also currently available in the market as both Augmentative and Alternative Communication (AAC), which can be used to add to the more usual methods of voice input and AT, to enable independence for individuals with special needs.

If the capabilities and activities together with the challenges of the motion-impaired user are identified, customisation of interfaces and the relevant devices becomes possible.

Sections [1.2.1](#) to [1.2.7](#) explore input and output solutions available for various modalities.

2.1.1. Arm, wrist and fingers based control

There are different types of adaptive keyboards available including those virtual and physical. Research on keyboard errors has been carried out and many customisable features are being integrated into standard computers. User models have been created to identify keyboard configuration requirements. The most common keyboard errors have been identified as long key press, difficulty in using modifier keys, additional key errors and bounce errors (Trewin and Pain, 1999). Trewin (2002) also introduced an invisible keyguard on the keyboard that could prevent overlap errors caused by tremors.

Cursor movements and sub-movements of the mouse have been measured for motion-impaired computer users (Keats, *et al.*, 2002, Hwang, *et al.*, 2004) and haptic assistance was integrated as a form of support for the experiments. Mouse clicking problems were analysed and a function that would freeze the cursor during mouse movements to reduce errors was incorporated successfully (Trewin, *et al.*, 2006). Customisation features such as sticky keys and sensitivity are available on mice while haptic feedback is available on touch based input devices. Soft keyboards introduced the use of self-adapting agents to continuously identify the needs of the user and keep adapting (Trewin 2004).

Indirect text entry systems with a predictive model using only one or two reliable keys were developed and tested by Baljko and Tam (2006). The users were able to make selections on a conventional QWERTY keyboard navigating in rows and columns with the help of containment hierarchy. They can also set up their personal profiles with choices of dwell period, target test and interface design.

When wrist movement is lost, an individual can still make use of their fingers, sometimes using both hands, to control a stylus or pencil to use Palm or any such handhelds that do not require wrist movement. For example, Pebbles was developed to cater to this group of individuals on PC keyboards and mice (Myers, *et al.*, 2002).

Restricted movement of the arm can also limit mouse and keyboard usage. Working with arm support makes the required movement more comfortable. Three types of arm support, Ergo Rest®, custom arm support with moveable and fixed modes (Schulze, *et al.*, 2002) have been identified.

Where users are unable to control standard or adapted keyboard and mice, Joysticks, Trackball and touchpads could also be used as text entry devices (Wobbrock, *et al.*, 2004; Wobbrock & Myers, 2006). Individuals with Cerebral Palsy have shown a higher mean information-processing rate when using the position joystick compared to when using a force joystick (Rao, *et al.*, 1999). Examples of gesture based input include EdgeWrite that uses unistroke gestures to assist users in writing by feeling rather than sight.

A typical computer based output modality would be visual with some auditory elements. The AudioDoom software enables blind individuals predominantly to perceive virtual worlds using 3D based auditory interfaces (Baloian, *et al.*, 2002). Haptic interfaces can also provide kinaesthetic feedback.

In the event of the user being unable to use the keyboard at all, soft keyboards, that are displayed on a screen where you can browse through the keys and select them, can be used (Gnanayutham, *et.al.*, 2004; Ace Centre, 2009).

Multi-touch contact enables many points of contact on screen, which include palm or fist as well as fingers. There is also the added characteristic of mobility to new media. Laptops, desktops and PDAs with both Windows and Mac operating Systems have similar interfaces, ergonomic design together with similar input, output and navigation. The interfaces that use natural and consistent input methods such as Microsoft Surface with a multitouch interface could be used but only with added mobility for all individuals within the environment of usage thereby making it ubiquitous and consistent.

Tabletops offer a potential for integrating low tech and light tech devices into a more powerful high tech environment by enabling the user to carry out tasks similar to that of a laptop and be mobile. Also, existing specialist mice, and keyboards may no longer be required, thus eliminating a need to counter errors relevant to mice and keyboards. Problems arising for the use of mice and keyboards by users with special needs have been eliminated by the introduction of self-adapting agents that can compensate for errors that are common among users with motor impairments (Trewin 2004, Trewin, *et al.*, 2006). Similar agents could augment existing tabletop software to compensate for motor difficulties when interacting via low tech props.

Object recognition on table top computers enables contact and connection with specialist low tech devices which are most often used as communication devices at home. The direct interaction functionality in tabletop interfaces requires no use of mouse or keyboard, which means more accurate hand movement will be required. The target group in this research are likely to have difficulty in making precise gestures or movements due to their limited control over their fingers, hand, wrist and arms. A further challenge would be that their existing customised tabletop might not be within reach from their specialist seating positions, and also that they may not be able to sit at Tabletops with existing form factors, which tend to be more like kitchen islands in form than tables.

ThinSight (Izadi,*et al.*, 2007) is a regular laptop based multi-touch interface that uses an optical sensing system placed behind a Liquid Crystal Display (LCD). ThinSight allows a much greater range of form factors than is possible with existing tabletop

technologies. As Thinsight form factors become available, motor impaired users of any seating position may become able to access tabletop interfaces.

The multi-touch and multi-user experience enables any member of the care circle to interact collaboratively without interrupting the user's control, thus creating further opportunities. This social opportunity could lead to much more effective communication, and a corresponding acceleration in the educational development of the target group of users for our planned research. Different features could be provided to meet the needs of different roles within the environment concerned, as well as adapting table top assistive technologies for home, educational and medical use.

2.1.2. Electromyography (EMG) based control

In the event where the arm, wrist or fingers cannot be used, Felzer and Freisleben (2002) introduced an electrically powered wheelchair controlled system using EMG signals belonging to any muscle chosen by the user by the name of the "Hands-free" Wheelchair Control System (HaWCoS) for users with extremely severe disability. In such a situation, the user is required to have reliable control over the chosen muscle and to become familiar with the system. This technology is successful outdoors and indoors for short distances. Felzer and Nordmann (2006) also introduced a further support "Hands-free" Mouse Control System (HaMCoS) that has similar requirement but they have also integrated a text editor LURD-Writer to advance this further.

2.1.3. Speech based control

Another form of communication are speech based input devices that have existed for aircrafts and in the form of interactive voice recognition for a number of years. However, the accuracy of recognition has always been a topic of debate due to accents, pronunciations and dialects. Nicol and colleagues (2002) explored the feasibility of any existing systems, and it was concluded from their experiments that challenges faced by the training of recognition engines need to be addressed prior to incorporating them into interactive interfaces. They developed algorithms that would enable the selection of large targets quickly regardless of their sensitivity or distance and small targets accurately.

As more intelligent systems are introduced, this technology is continuously improving. A speech based cursor control system was introduced by Karimullah and Sears in 2002. An addition to this Dai and team (2004) developed a grid based cursor control system using speech input to overcome problems identified in existing speech based systems.

2.1.4. Eye based control

Various eye tracking software and hardware have been researched for over a couple of decades. To enhance the performance of these pointing devices, zoom functionality was added (Bates and Istance, 2002). Children with severe motor impairment are able to use EyeDraw, an eye tracker based drawing tool to communicate and recreate (Hornof, *et al.*, 2004). To use an eye tracker for drawing, the user needs to be able to carry out task analysis at visual, perceptual and oculomotor task levels. Another software application, Whisper, helps people with impaired auditory abilities recognise speech errors (Baloian, *et al.*, 2002).

2.1.5. Head control

Head switches can be used when there is no control over the arms. Depending on the control capability of the head one or two switches can be used to navigate the screen and make selections (Terrell, 1985). This can however be quite painful and potentially cause repetitive strain injury. The user also tends to get tired quickly.

2.1.6. Brain controlled interfaces

People in Comatose and locked-in syndrome or quadriplegic who do not have control over any limbs and possibly head or eyes can communicate using EMG signals (Doherty 2001, Gnanayutham, 2008). Extensive research in this field has been carried out, but the availability of such devices has been fairly limited.

2.1.7. Physiological sensing

Skin can also be used to detect emotions. Although this is not a form of normal communication, it can be quite useful. Galvanic Skin Response (GSR), a biometric control interface was developed by Moore and Dua (2004) using a type of electrodermal response which measures electrical conductivity on the skin generated by fear, excitement or anxiety. Accuracy can be customised, monitored and this technology can be used to monitor emotional response of non-verbal locked-in individuals.

2.1.8. Conclusion

As seen above, most assistive devices are designed to overcome limitations associated with specific body functions or structures. These tactics are primarily biomedical.

Motor impaired individuals participate in various activities in their home, work and education environments and interact with those in their environments. This creates the demand for platforms that make these activities viable. There are significant opportunities for social elements in multi-touch and multi-user platforms, however there is currently little research attention paid to actual needs arising from biomedical conditions. Social participation and activities appear to be overlooked in both cases. Individuals with a similar health condition may have varying capability, and individuals with different health conditions may have similar capability in carrying out tasks. This may be due to environmental and personal factors. Thus, users could end up with assistive devices that are unsuitable for day to day tasks, inappropriate for the environment in which they need to be used and unfit for the individual's personal experience, familiarity or choice.

Rather than making a biomedical decision, if the AT device was chosen strategically, consulting other individuals from their environment and taking into account the tasks that need accomplishing, in the choice and use of AT devices, AT and AAC should increase functional ability and contribute towards enhancing the overall capability of individuals with motor impairment.



University of
Sunderland

Research Plan

BEYOND BODIES: SITUATING ASSISTIVE TECHNOLOGY
FOR YOUNG CHILDREN WITHIN

WORTHWHILE SOCIO-DIGITAL SYSTEMS

- December 2008

Jennifer George

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Chapter 1 - Research Summary

In the decision making during a child's development, a team of people including family members, members of staff at school and medical practitioners are involved, thus creating a care circle. The responsibility of providing the child with suitable assistance and guidance lies with the care circle. This care circle would typically consist of parents, siblings, peers, teacher, SENCO, ICT coordinator, advisory teacher, LSA/TA, educational psychologist, paediatrician, Speech and Language Therapist, Occupational Therapist and Physiotherapist (Ace-Centre, 2008). A child communicates with the members of care circle using low tech or high-tech assistive devices and at times a variety of different devices. A child spends approximately six hours in school. The responsibility of reducing the disability of the child depends greatly, not only on their therapists and teachers, but also on their parents. Parents can accept and understand the child's special need, but they also need to help the child reduce disability by increasing independence. Although parents may find it comparatively easier to perform the children's low-level life skill tasks for them, saving time and energy, the children need to be constantly encouraged to carry out low-level tasks themselves with the challenges gradually increased. Parents also appear to be the only constant part of the care circle as the school, teachers, therapists and carers can keep changing (Ace-Centre, 2008) as the child continues to make progress.

This research focuses on children between the ages of 5 and 7. However, interaction for the purpose of this research is with members of their care circle only.

The research questions to be addressed by this research are:

1. What are the implications of ICF's biopsychosocial approach to disability and assistive technology?
2. How can we overcome the limitations of a biomedical approach to impairment?

3. Can worth centred approaches be used effectively to improve socio-digital systems for the care circles of young children with extensive motor impairment?

Chapter 2 - Ace Centre and SpeechBubble Project

The Ace Centre is an assessment centre for children with communication difficulties. A team of experts at Ace Centre carry out the assessment and recommend communication and assistive devices with regular reviewing.

Ace centre manages a database of assistive devices at <http://www.ace-north.org.uk/userStatus/vocapages/main.asp> which functions as a support system for selecting AT devices if you know the specific functional needs of the device. The Ace Centre is currently working on a project that is to be completed in 2009 named SpeechBubble which is an advanced support tool. This support tool <http://www.ace-centre.org.uk/index.cfm?pageid=6B18152B-3048-7290-FE99D2573C6EAC3E> is proposed to include three main features: software, talker and vocabulary. Software section deals with access and interface related features while talker addresses input and output methods and vocabulary looks at complexity and navigation of words.

According to Matching Persons to technology (MAIR, 2004), up to 75-80% of assistive technology devices are being abandoned. The reasons include the technology not matched well enough to meet the individual's need, little or no training provided and care circles not accepting technology.

The International Classification of Functioning, Disability and Health (ICF) classifies functions and disability into body functions, structures, activities, participations of individuals and the contextual factors of individuals as environmental factors and personal factors (ICF, WHO 2008). It provides a basis for understanding and describing impairment and helps construct meaningful practices related to its consumers by combining the medical and social approaches to disability. With each individual's capability being different and dynamic, choosing reliable assistive devices that would best suit their needs can be very challenging, thus requiring a biopsychosocial approach (WHO, 2001). A choice of assistive technology that

merely deals with a static physical nature of disability, moves away from universal design, creating a biomedical approach. Even when the biological conditions of the individual are similar, the environment and care circles can make the demonstrable capability of the individual different.

A capability model extended contextual and environmental factors and what they support could be developed. Socio-digital systems explore the relationship between people and technology in order to understand how technology could be designed to support human values considering psychology, sociology, design, computer science and hardware engineering (Microsoft, 2008b). This can be used to evaluate user needs during the selection and effective use of communication and educational environments, both physical and virtual for the development of socio-digital systems.

A capability model has to extend to environmental, personal and social factors. The ultimate model could be used by a designer to enable a 'near perfect' support environment, both physical and virtual, and thus go beyond merely fixing bodies.

This research proposes to extend the existing technical approach to a biomedical approach including some personal and environmental factors. The research thus aims to design, develop and evaluate an applicable model for children with severe physical impairment.

Chapter 3 - Request from ACE

“...its aims, its outcomes, its methods and the proposed involvement of ourselves and any other partners. Presumably there is a formal project proposal at the University.

We would need to understand any implications regarding time from our staff and other costs (eg travel) and whether these would be reimbursable.

We are supportive of collaborative working but our financial situation at present is very tight, therefore we would need a really good understanding of what is involved before giving any commitment of ACE resources.

Maybe you could describe how your research fits in with our 'speechbubble' project which we mentioned when you visited, as there may be some related work there....”

Chapter 4 - Research Approach

This research aims to investigate the effectiveness of socio-digital approaches to the selection and use of assistive technologies for young children with extensive motor impairments. The research follows the extended methodology of design cycle (Microsoft, 2008a) to address the research questions.

1. Understand: Focusing on human values for research, consisting of reflective thought and conceptual analysis;
2. Study: Developing deeper understanding of the values identified in the first step;
3. Design: Reflect on the design goals and relate them to social settings;
4. Build: Low tech or high tech models are built;
5. Evaluate: Evaluate models built in step 4.

The research questions are addressed in three phases. This section discusses the research question addresses, methods and methodology, requirements from the Ace Centre and outcomes of each phase.

4.1 Phase 1

4.3.1. Aim

This phase of the research would last for four months and aims to look at the scope required to understand children's use of AT and contrasting different approaches to the choice and selection of AT understand the care circle's involvement by developing personas that would help in the development of the prototypes and further development of SpeechBubble.

4.3.2. **Research Question**

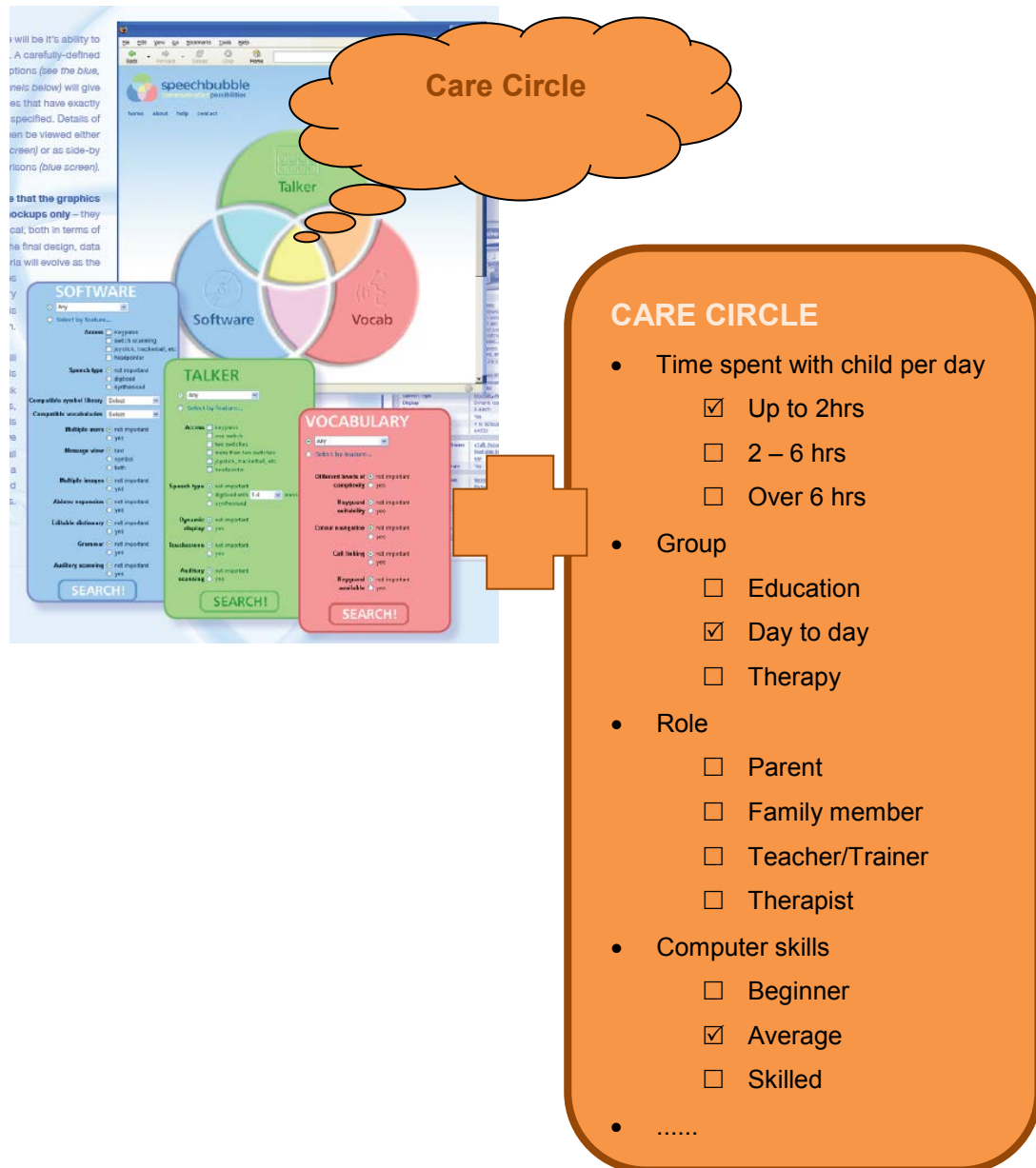
What are the implications of ICF's biopsychosocial approach to disability and assistive technology?

4.3.3. **Methodology**

The initial exploratory research would identify and analyse the current usage of assistive technology in a socio-digital context. Preliminary information gathering has been undertaken using contextual inquiry and participant observation at a school for motor impaired children, The Ormerod School and an impairment assessment centre, The Ace-Centre (both in Oxfordshire). The researcher having previous experience in working with young children in speech therapy was also able to be a member of the team and be involved in class activities during the participant observation making it a contextual analysis. This was followed by semi-structured interviews with teachers, therapists and consultants who made up the care circle. Information with regard to the medical diagnosis, use of assistive devices, scope of main stream education, and any special characteristics such as interest or disinterest in activities and support of family were documented.

Caring for a child with physical impairment not only includes assistive technology but also members of the family and those directly involved in the education and medical needs of the child, requiring a socio-technical phenomenon. Based on the ICF's definition of capability, information on body functions, structures, activities, participations of individuals and the contextual factors of individuals as environmental and personal factors, socio-digital system models can be developed. Performance review and evaluation needs to be carried out regularly with the care circle. The factors that affect capabilities and any models that have been created to identify different factors will also be looked into from existing literature. Information would be drawn from existing literature, interviews from experts working with this special group of children and children who are both able and disabled. Members of the care circle could be modelled in the form of personas (Pruitt and Adlin, 2006). The relationship between the characters, could also be constructed in the form of

locales. The identification of such care circle at the early stages of the research would be beneficial for continuous feedback throughout the research.



Worth maps would be designed to identify the means to end chains thereby making the identification of a worthwhile socio-digital system possible. While medical practitioners diagnose needs, occupational therapists evaluate capabilities, modify environments and provide therapy and support to enhance the lifestyle of the individuals. The bridge between the medical approach and the capability approach

would be identified. In order to address the limitations of the medicalised approach to impairment, a user centred ICF based bio-psycho-social approach would be employed. For this purpose, the NHS assessment methods will be evaluated against the care circle based assessment using the Ace-Centre as a case study. Thus the limitations of a socio-technical approach would be identified.

4.3.4. Involvement from ACE Centre

A series of evaluation reports on the existing SpeechBubble project would be provided to ACE during this phase. Evaluation with users would be conducted by way of semi-structured interviews and user walkthroughs. During the evaluation, information on children who are currently using AT, together with members of their care circle, would be gathered to develop personas. The number of members per care circle is expected to be 5-7. The information may include, age, nature of special need, AT devices currently used, how members of respond to using the communication device with the child, etc. This could be done by way of a questionnaire and/or interviews developed by the researcher with information providers. Information could also be obtained by observations either at the Ace-Centre or Ormerod School¹. The interviews with the researcher could take up to 2 hours in total to obtain information for the first time. Following the initial development of personas, feedback from the assessment team at the Ace-Centre could enable identifying the positive and negative attitudes of members of the care circle. For example, whether a parent would rather carry out the task him or herself than bear with the child and encourage independence. This feedback is estimated to take around 1hour in total every month. This should help further identify the needs of the child and members of the care circle in addition to the requirements stated by them. This iterative process could be carried out either by email or telephone conversations.

¹ Permission to be obtained

4.2 Phase 2

4.3.5. Aim

The second phase of the research lasts for 4 months and will design the extensions to SpeechBubble. The personas built in together with the opportunities for extension of the SpeechBubble identified in phase 1, would be used to identify possible design interventions. For example, SpeechBubble could be extended to include information on technical capability, time spent with child using the device, role of the care circle member, etc. At the end of this phase, clear guidelines for the technical implementation of SpeechBubble extensions would be developed in preparation for the final phase of the proposed research.

4.3.6. Research Question

How can we overcome the limitations of a medicalised approach to impairment?

4.3.7. Methodology

A design intervention to fill the gap identified in phase one would be proposed and refined using the personas first and thereafter cooperative evaluation. The care circle would be involved in the development of the design intervention. Children too would be included in this process by way of continuous contextual inquiry to gather non-verbal feedback and observe exploratory patterns; prototype usage to identify how children communicate with technology; participatory design to get children to voice their opinions and be partners in design. The requirements for the proposed design intervention would be specified based on the analysis of the whole usage experience, and not just children's motor capabilities.

Personas of the care circle would be used to help guide decisions during the design and developmental process (Cooper, 1999). Multiple personas will help identifying behaviour patterns including goals, skills, attitudes and environments.

4.3.8. Involvement from ACE Centre

Paper or low fidelity prototypes would be built, and feedback would be obtained. Walkthroughs of the paper or low fidelity prototypes would be carried out with reference to the personas that represent each member of the care circle. For example at this point it would be possible to identify how a persona would make decisions on the selection and use of an AT device. It will also be possible to identify possible any conflicts in choices or opinions. During this time, feedback from Ace Centre in house experts and the experts evaluating SpeechBubble would also be valuable. This could be done by face-to face meetings, telephone conversations or email. Communication for 1-2 hours every month would be sufficient for this purpose.

4.3 Phase 3

4.3.1. Results/Aim

This phase of the research would last for 4 months and aims to implement the design intervention identified and refined in the previous phase. It will then evaluate the SpeechBubble extensions, assessing the extent to which these result in a more comprehensive support system.

At the end of this phase, there would be a tested version of an extended SpeechBubble available for immediate use. This would also be accompanied by an evaluation report. At this point, it would also be possible to propose what changes and improvements could be made to the SpeechBubble Project as a whole in the future.

4.3.2. Research Question

Can worth centred approaches be used effectively to improve socio-digital systems for the care circles of young children with extensive motor impairment?

4.3.3. Methodology

Phase two of the research would have met the needs of the personas, and real users would be used in validating the framework in phase three. A worth-centred development (WCD) approach would be taken having been receptive to the ideas and opinions of the care circle. The six meta-principles of Worth-Centred Design namely commitment, receptiveness, expressiveness, inclusiveness, credibility and improvability would be followed (Cockton, 2007). Preferences, acceptability and contextual factors will be integrated into the model based on the information derived from the WCD. The design and development of the socio-digital systems would be of an iterative nature as with the WCD involving the care circle continuously.

Motivating factors behind what makes the usage experience valuable will be identified to enhance the overall worth. These requirements will be used to build low fidelity prototypes of the modelling tool, which will be tested with the care circle, and will consequently be followed by the development of a high fidelity prototype built using Macromedia's Flash. The high fidelity prototype will be evaluated by the care circle, including the stakeholders and children.

4.3.4. Involvement from ACE Centre

The opportunity to work with a beta version of current SpeechBubble as the basis for integrating additional features would be needed. This would make it possible to test the proposed extension with the experts at ACE and if possible a selected number of users. The building of the technical extension could take approximately two – four weeks. If appropriate, ACE's technical expert could collaborate here or the researcher could work independently (if access is granted to a beta version). Advice from in house technical expert during this time would be very beneficial. Testing could be arranged according to the availability of the experts at ACE and this would determine the total contribution to this phase.

The design intervention should help to improve individual capability and increase worth not only by the selection or re-design of assistive device but also, and perhaps predominantly, interactive support for effective usage.

4.4 Time Table

Phase	Task	Start	End
1	Evaluating and developing Personas	March 2009	June 2009
2	Designing extension	July 2009	October 2009
3	Integrating and testing extension	November 2009	February 2010

4.5 Budget & Finance

There will be no travelling required by staff or clients at Ace Centre for the purpose of this research. Overall, no ancillary expenses are expected to be incurred. If the need for funding arises during the research, this could be reconsidered.

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Mobility Models

The following mobility models and their corresponding tables go beyond individual written findings to explore roles of models in extending *Committedness*.

4.1.1 Activity 0 – Assumption of mobility

The first mobility model is based on initial assumptions where the roles and relationships between members of the Care Circle are *Expressed*.

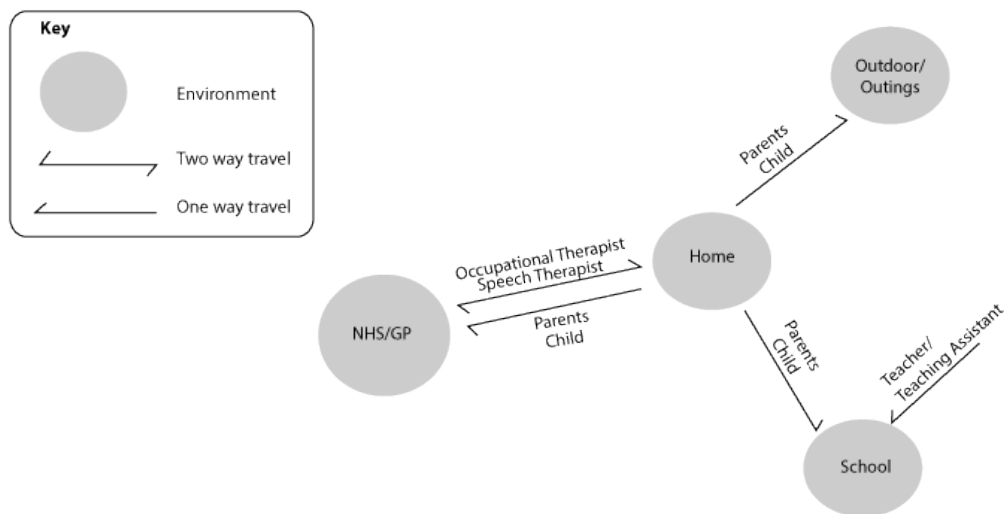


Figure 0.1 – Activity 0 Assumption Mobility Model

Further to Activities 1-4, further members of the Care Circle were identified. Figure 4.3 shows that the Care Circle can be extended to support workers and teaching assistants.

4.1.2 Activity 1 Mobility Models

This mobility model is based on the findings of Activity 1.

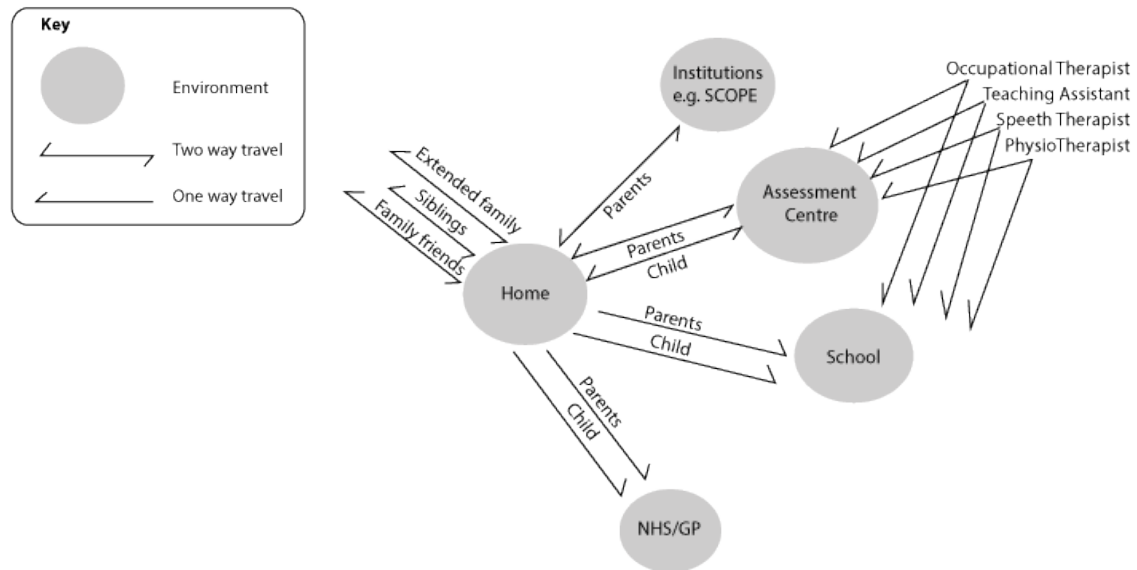


Figure 0.2 - Activity 1 Mobility Model

4.1.3 Activity 2-3 Mobility Models

Mobility model 2-3 is based on Activities 2 and 3. A single model has been created for both these activities as they were both conducted in the same environment.

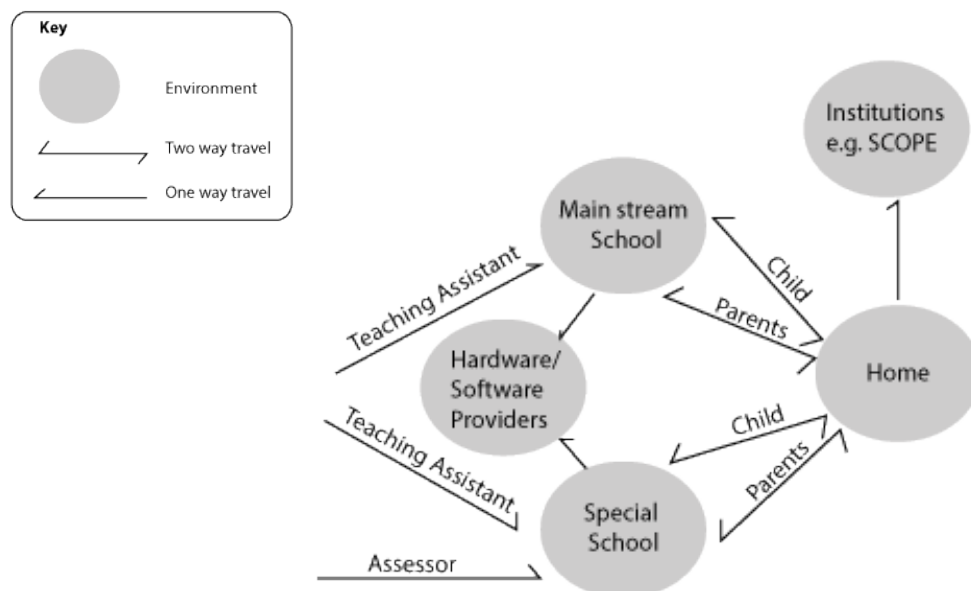


Figure 0.3 - Activity 2-3 Mobility Model

The above mobility model shows that the communication structure differs according to the purpose and goal. While mobility model 1 shows an extended assessment for

multiple purposes where mobility model 2-3 shows an assessment done for a school environment.

4.1.4 Activity 4 Mobility Models

Activity 4 was visualised as Activity 4 Mobility model.

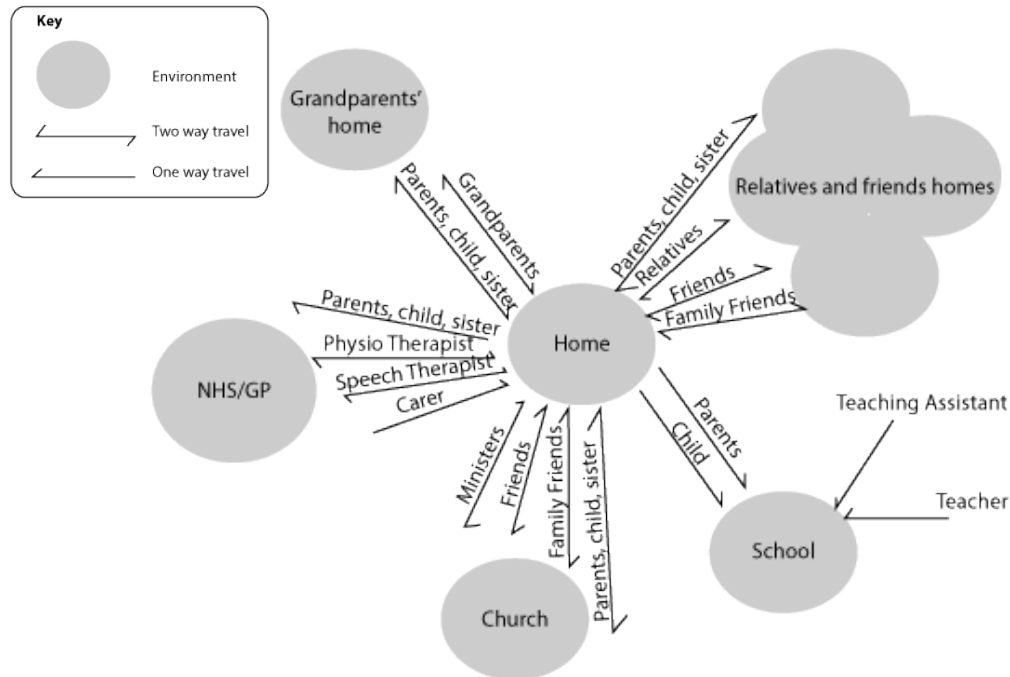


Figure 0.4 - Activity 4 Mobility Model

Flow model 4 shows the Care Circle and communication focused on a child. A new dimension of frequency of contact is also identified.

The four mobility models visualise expressivity of *Beneficiaries*. This identification helps focus on increasing communication and reducing travel.



SpeechBubble

A Which? guide to
communication aids

Providing a searchable online guide to
the technology that can help people
with communication disabilities

ace
centre
Giving people a voice...

“We need a Which? guide to communication aids”

Attendee, ACE Network Day, Jan 2007

When we buy a camera, washing machine, or a mortgage, many of us rely on specialist magazines and websites that compare and contrast what's available. But, unbelievably, nothing similar exists for the hundreds of communication aids that are now produced – devices like the ‘talking’ computer used by Stephen Hawking, for example. These aids aren't a luxury; they're vital in giving disabled people choice and control over their lives. There's now a real and urgent need for parents, professionals and carers to have access to a single source of comprehensive and unbiased information about equipment that enables people to speak.



Why is this important?

As many as 1.5 million people in the UK have a communication disability. For those whose disabilities prevent them from speaking, a communication aid is literally their voice. And, unlike choosing a camera, getting the choice of aid right has an immeasurable impact on their quality of life. Get it wrong, and they have little chance of communicating effectively with the world around them. But matching a communication aid to the needs and abilities of an individual is a very complex process, and an in-depth knowledge of the capabilities of each aid is absolutely essential in making the right decision.

How we can help

The SpeechBubble project aims to provide a unique searchable website through which therapists, parents, carers and communication aid users themselves can compare and contrast the key features of the aids, provide an insight into how they can be operated, and make sense of the bewildering variety of communication software that's on offer. The value of such a website as a professional resource, assessment support tool and teaching aid is immense, and will give all those involved in the decision-making process the reassurance that all the options have been considered.

Case study: Replacing the irreplaceable



Milan, a bright and lively 17-year-old, has cerebral palsy. He has no recognisable speech and little voluntary movement, but he can control his head just enough to click a small switch that's attached to the headrest of his wheelchair. Four years ago his life changed forever when he started using this switch to control a communication aid with an artificial voice.

Recently this device started to fail. It's vital that it's replaced as soon as possible, but it's no longer manufactured. Instead there are now over 100 alternative devices available, all with a multitude of features and options, all with benefits and drawbacks. His needs are complex: he has to be able to control everything on it with just one switch, and it must run all the communication software that he currently uses. It has to fit his current wheelchair but be portable enough to be used away from it, and its screen must be bright enough to be used in direct sunlight. And this is just the beginning of the critical list of features required. Any wrong choice will dramatically affect his ability to communicate.

SpeechBubble will provide Milan, his parents and his support team with a quick and reliable means to search for a list of suitable replacements based on these and many other criteria. With many communication aids like these costing over £5,000 pounds each, the value of providing an informed choice cannot be underestimated.

What is a communication aid?

Communication aids help individuals to communicate more effectively with those around them. They range from simple letter boards to sophisticated pieces of electronic equipment. It's the ever-expanding range of the latter that SpeechBubble aims to tackle.

An electronic communication aid uses an artificial or pre-recorded voice to speak letters, words or phrases that the user has selected. It can be a device that has been specifically built for the job and does nothing else, or a standard computer running specialist communication software – with the added benefit of being a computer as well.

There are a surprising number of ways to operate these aids. The most obvious method to access the stored speech is by pressing buttons or a touchscreen on the device, but this might not be possible for individuals with physical disabilities. Switches and other specialised equipment are available that allow access through any controllable movement of the body. That's not just limb movement, it includes head control, sucking and blowing - even eye movement alone.

It's not essential for the user to be able to read text in order to use a communication aid. Many aids are based on symbols and still provide full functionality to communicate with others.

How the problem arose

Communication aids have been around for over twenty years, and for much of that period it was possible to keep up-to-date with new devices purely because of the limited number of products available. But developments over the last five years have resulted in an explosion in the number of powerful new communication aids. This is great news for people with communication disabilities, but it's meant that it's almost impossible for parents, professionals and users to keep pace with developments and make properly informed decisions about matching the best equipment to the needs of the individual.

Why do we know this?

We know this because our own work as an assessment centre for children with communication difficulties has forced us to produce a simple and incomplete pilot website that contains basic hardware details of many communication aids. This website, currently located at <http://tinyurl.com/2ycxj8>, now attracts up to 600 hits a month from people across the world.

The feedback from this site has been clear and consistent: hardware details, although useful, are not nearly enough. To make a truly useful resource, substantial additional information is desperately needed about the relevant communication software, vocabularies, symbols and methods of access, along with the ability to carry out side-by-side comparisons. And it all has to be regularly updated.

No such resource currently exists because of the time, volume of data and specialist knowledge required. But with the staff and technical resources we have at the ACE Centre, combined with the hardware data that we already hold, we are uniquely placed to make such a website a reality.



How it might work

The key to the site will be it's ability to search effectively. A carefully-defined set of search options (see the blue, green and red panels below) will give users a list of devices that have exactly the features they specified. Details of the devices can then be viewed either individually (far right screen) or as side-by-side comparisons (blue screen).

It's important to note that the graphics on this page are mockups only – they are purely hypothetical, both in terms of look and content. The final design, data and search criteria will evolve as the project progresses and may be very different from this interpretation.

The final website will feature far more than is shown here. Feedback forms, breaking news, suppliers' details and comprehensive help facilities are all planned, along with a glossary of terms and acronyms.

The mockups illustrate the website's search and product display capabilities. The central Venn diagram represents the intersection of three key features: Talker, Software, and Vocab. The search panels allow users to filter products based on these features and other criteria. The product comparison screens show how specific devices are presented to the user.

SOFTWARE

Any [dropdown]
Select by feature...

Access ☐ Keypress
☐ switch scanning
☐ joystick, trackball, etc
☐ headpointer

Speech type ☐ not important
☐ digitised
☐ synthesised

Compatible symbol library [Select]
Compatible vocabularies [Select]

Multiple users ☐ not important
☐ yes

Message view ☐ text
☐ symbol
☐ both

Multiple images ☐ not important
☐ yes

Abbrev expansion ☐ not important
☐ yes

Editable dictionary ☐ not important
☐ yes

Grammar ☐ not important
☐ yes

Auditory scanning ☐ not important
☐ yes

SEARCH!

TALKER

Any [dropdown]
Select by feature...

Access ☐ keypress
☐ one switch
☐ two switches
☐ more than two switches
☐ joystick, trackball, etc
☐ headpointer

Speech type ☐ not important
☐ digitised with 1-4 [dropdown] mess
☐ synthesised

Dynamic display ☐ not important
☐ yes

Touchscreen ☐ not important
☐ yes

Auditory scanning ☐ not important
☐ yes

SEARCH!

VOCABULARY

Any [dropdown]
Select by feature...

Different levels of complexity ☐ not important
☐ yes

Keyword suitability ☐ not important
☐ yes

Colour navigation ☐ not important
☐ yes

Cell linking ☐ not important
☐ yes

Keyword available ☐ not important
☐ yes

SEARCH!

Comparison Screen 1: You've chosen to compare 3 products

akeeter	TalkAbout	TrueVoice VP
2005 Comes with R-50s down-based communication in with OCChak synthetic in and 128 minutes of ad speech as standard. The Johnson PCS symbol library added... more details	2005 Comes with R-50s A rugged communication aid with a built-in camera and Gettext system. Uses Windows Vista, but the system is locked so that no other software can be loaded... more details	2007 TalkTalkTalk A heavyweight aid that's primarily designed for wheelchair mounting. The TalkBox features an exceptionally bright screen and... more details

Comparison Screen 2: Lexicon

click for Lexicon images

Supplier(s): Liberator Ltd
Size (cm): 20.5 x 2.7 x 6
Weight: 1kg
Audio prices from £2400
Accessed by: Direct keypress, single
or dual switch scanning, mouse,
joystick, headpointer

The Lexicon, first available in the UK in 2005, is a Windows-based
communication system with a large 12.1 inch colour touchscreen. It comes
with OCChak synthetic speech and 128 minutes of digitised speech as
standard. The Mayer-Johnson PCS symbol library is included, and the choice
of software options includes Liberator's VIP range. Note that although the
device runs using Windows CE, the communication software takes over the
system completely so it can't be used as a standard Windows computer as
well as a communication aid.

Further details of the Lexicon

Compatible communication software:

- eTalk Pictures
- Portable Impact
- VIP

Compatible vocabularies:

- WordPower
- Picture WordPower
- Yakobity
- VocabNet
- AdLib

What we intend to do


We can provide a comprehensive and unique online source of information where speech and language professionals, parents, carers and people with communication difficulties can compare, contrast and identify the communication aid equipment that may best suit their own or their clients' needs.

How will we do this?

- By collecting and maintaining selected details of communication aid hardware and software.
- By developing, testing and launching an accessible website containing this data.
- By putting in place a mechanism for the continuing maintenance and updating of the site and its contents.
- By forming an External Advisory Group of communication aid professionals and users to oversee the development, content and functionality of the website.

Who will benefit?

- SpeechBubble will provide a professional assessment resource for speech and language therapists, occupational therapists, IT practitioners and teachers to ensure that they have the most up-to-date knowledge when advising and recommending communication equipment for their clients
- Individuals with communication disabilities and their parents/carers will receive a more consistent and efficient level of service from communication professionals, and they will have the reassurance that all the options have been considered.
- The website will be a key teaching resource for student therapists and the continuing professional development of qualified practitioners.
- SpeechBubble will act as a first-stop information point for any Individuals with communication disabilities and their parents/carers who need to know more about communication aids, and it will enable them to ask the right questions of the professionals working with them.
- The compare and contrast features will be invaluable for existing communication aid users who wish to ensure that their existing equipment remains the most suitable for their needs and abilities.

A woman and a young girl are looking at a communication aid device. The woman is on the left, and the girl is on the right. The device is a small, rectangular, white electronic device with a screen and buttons. The background is a soft, out-of-focus outdoor setting with trees and foliage. The entire image has a light blue tint.

“Without my
communication aid
I can’t say what’s
in my heart and in
my head.”

SCOPE Communication Aids Survey respondent, 2007

Timescale & strategy

SpeechBubble will take twelve months to develop and test.

There's absolutely no point in producing such a website unless it's regularly maintained, so a post-launch strategy will ensure that this resource remains indispensable.

Timetable

The project will be divided into four phases:

- **Pre-development Phase**

A development team will invite leading speech and language professionals and representatives from the communication aid community to form an External Reference Group. This group will play a key role in producing specifications for the site's criteria. From this, a functional specification will be produced and put out to tender. A suitable web developer will subsequently be contracted. Work will commence on data gathering and product photography for the site, and will continue up to and beyond the launch phase.

- **Development Phase**

An alpha version of the site will be produced and trialled with targeted user groups. After feedback, the process will be repeated for a beta version. Following the final data checking and population, a public version of the site will be prepared and approved. A launch venue will be identified and publicity will be produced for the beneficiaries, therapy professions, conferences, general public and relevant journals.

- **Launch**

The website will be launched at a high-profile international conference such as ISAAC.

- **Post Launch Phase**

Uptake of the site will be monitored and, after a suitable period, case studies demonstrating it's effectiveness will be prepared. Leading communication aid suppliers will be approached and, following confirmation of continuing funding for maintenance, the site will continue to be publicised and its useage monitored.

Evaluation

A formal evaluation of the project will take place immediately after the launch and will be presented at relevant national conferences and published in relevant professional journals. Reviews will then take place at regular six-monthly periods thereafter. Data will be collected from website user statistics and will be made publicly available.

Exit Strategy

Discussions with leading communication aid suppliers have already indicated that pending a successful take-up of site usage, funding would be available for the continuing maintenance, hosting and updating. This funding would be supplemented by advertising income through the site itself in the form of banner adverts.

Project Management

The ACE Centre project team will consist of a project leader, two speech and language therapists, a communication tutor and a project officer. An External Reference Group will oversee the project and will consist of invited leading speech and language therapists, representatives from the communication aid suppliers and communication aid users.



Budget & funding

Developing SpeechBubble will cost a total of £79k. The project team have detailed costs and a full project plan for inspection.



Project Budget

Pre-development Phase

Staff costs: £21k (data gathering and preparation, meetings with external reference group, production of functional specifications, endorsement materials, project management)

Other costs: £0.5k (printing, dissemination materials)

Development Phase

Staff costs: £16.7k (development, data gathering and preparation, trialling, project management)

Web development: £21.2k

Other costs: £0.3k (hardware)

Launch

Staff costs: £4.1 (publicity preparation, event attendance, project management)

Launch event organisation and venue costs: £3k

Launch event marketing and publicity: £3.8k

Post Launch Phase

Staff costs: £6.7k (continuing data maintenance, case study preparation, meetings and negotiation with suppliers, project management)

Other costs: £1.7k (printing, exhibition costs and marketing)

Current Funding Situation

Total cost to be raised: £79k

Funds already received:

£5k from the Gatsby Charitable Foundation (underwritten by core grant)

£21.2k from the Geoff & Fiona Squire Foundation

£5k from CHK Charities Ltd

£1k from Coutts Charitable Trust

£1k from the Ann Burn Trust

£500 from the Saved to Serve Trust



We are a registered charity that provides help for those who need to understand and use communication aids and assistive technologies. Our therapists, teachers and technologists offer a comprehensive assessment service for young people with complex physical and communication difficulties. We also offer training, information and consultancy for both parents and professionals. With over twenty years of experience in our field, you can be assured of the quality, independence and expertise of our work.

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Company Reg No: 2961300
VAT No: 663587987

The Centre Interviews

‘The Centre’ – AT Evaluation Centre

Monday 28th January 2008

3pm - 4.30 pm

SLT (Speech Therapist) & PO (Publications Officer)

Duration: 10 mins

PO is responsible for developing and maintaining their website and the database consisting of Assistive devices and suppliers. He is currently working on a project ‘SpeechBubble’ providing a searchable online guide to technology that can help people with communication disabilities. The website is targeted towards Speech and Language Therapists and parents/guardians who are familiar with the assistive devices. Document on outline of the project was supplied.

He believes that my research would be something that can be added to what they are working on (which is scheduled to be completed by mid 2009). i.e. The model from my research could help in connecting capability and device while his website/database would help in identifying the device and the supplier. He also added that this capability model would make the existing database useful to a novice.

SLT (Speech Therapist) & OT (Occupation Therapist)

Duration: 1hr 30mins

- **Experts’ qualifications and experience:**

The assessment team comprises of an Occupational therapist, teacher, Speech and Language Therapist and at times the technical officer. These experts are experienced in both education and health.

- **What, if any, standard scales of measurement are used to assess this specific special need:**

‘There are no standard scales of measurement for non-standard users’ - SLT

- **Methods and techniques used, length of typical assessment and specialist equipment and resources**

The method in which the child is directed towards ACE can vary. Depending on the funding available, this can be through their school, the NHS or private. Once the relevant sources have contacted ACE, a referral form is sent out to be completed by the party contacting ACE. This form is used to identify how ACE could help the child.

On receipt of the referral form, the teacher, SENCO, ICT coordinator, Advisory teacher, LSA/TA, educational psychologist, paediatrician, SLT, OT, Physiotherapist and any other persons listed as involved with the child's development in the referral form will be contacted. These professionals are sent out individual detailed forms to understand the child's interests, hearing abilities, vision, face-to face communication, education, seating and positioning, mobility, use of ICT and any additional information. Guidelines of a video together with an information form are also sent to the parents/guardian. The video is to analyse how the child communicated with other children, adults, plays, interacts and has conversation. Using the video, they are also able to assess the motor capabilities. Based on the referral and the video an assessment plan is developed and the appointment is set for evaluation.

The assessment usually takes up to half a day. The assessment team primarily uses the 'Wizard of Oz' method to analyse the child. During this time, seating and positioning, control of technology, use of computer and communication capabilities are assessed and an action plan is put together with any educational, training and support issues.

- **What criteria guide the recommendation of specific aids or assistive technologies?**

There is no formal tests, measurements or functional models. The choices are made based on the information forms and the assessment. The base line is language capability; it is not possible to separate learning and communication thus suitable technology for depending on accessibility and the curriculum followed are suggested.

- **Review frequency**

Not applicable, as ACE-Centre has absolutely no control over it. Children returning for review or reassessment depend entirely on the institute they belong to and the funds at their

disposal. SLT also mentioned a 4-year-old girl named Tamzin who was first assessed at 15 months and has been reviewed thrice since with a lot of improvement (She is at Ormerods). SLT also stated that the younger the child is when assessed the more chance of improvement. Jackie added that the assessment was a deliberately loosely structured around task and activity analysis as it was impossible to have a checklist.

- **Success rate of recommendations and choices**

It is not possible to comment on the success rate due to the lack of feedback/review

- **Who are the manufacturers of the devices**

The list of suppliers are in the website. ACE-Centre does not directly communicate with the manufacturers. There is one manufacturer in UK, one in Brazil and many in the US. In the past some of them have got in touch with The Centre for feedback and suggestions during their development. ACE also has some in-house developers.

- **How configurable are the devices**

All low tech, light tech and high tech devices are configurable

- **Do you ever develop the devices or place orders for specialized/customised devices**

The needs for configurations have risen. Most software based needs are easily met as most software are PC based and this would probably take the form of a plug-in or add-on. Whereas hardware or systems needs also arise but as the organization concentrates on abilities rather than disabilities they have always found some available device that they could suggest.

- **Collect sample forms and any information packs or leaflets**

- A tutorial on ACE-Centre's approach & vocabulary
- A guide to SpeechBubble
- Referral form
- Information forms – professionals, parents/guardians
- Assessment plan form
- Assessment form
- Video guidelines

- Current project related leaflets : Toys2Talk, AccessAbility, Training Courses, Communication, Newsletter 2006

- **Other recommendations**

- ‘Clicker’ software (Open framework) used in mainstream education
- COPAM (Canadian Occupational Performance Measure)
- Assessment model developed by Patrick Poon
- ‘Pathfinder’ PRI device
- AFASIC – AT assessment organisation
- FAST – VR based assessment
- DASHER – a Cambridge student David Cai’s downloadable free software that incorporates – eyegaze in a unique way

- **Future**

SLT is willing to give feedback/information in the future on the research if I can make an appointment on any of their information days, which are held every months. She also said that she would talk to her director about the research and if requested consider a possibility of making it a collaborative research. SLT mentioned current collaborative work with Universities Durham, DeMontford and Leicester, Manchester. As the government has stopped funding ACE-Centre they are currently considering collaborative research. SLT suggested that a communication specialist would be useful during the entire research.

School Observation

School for CP Children under 5

Tuesday 29th January 2008

9.15am to 3pm

Description of children

- At 9.15am SLT guided me to the classroom of 6 four year olds; 3 boys and 3 girls. All six children were held by the AT's in position for their activities and no child was on a wheelchair.
- Child R – CP, quadriplegic, had no control over any of his limbs and could not sit in position by himself, couldn't speak and does not give definite yes/no answers.
- Child W – Not CP, has severe muscular impairment, cannot speak, tube fed, cannot speak clearly and can make noises – uses sign language although, by nature is very lazy/definitely not a morning person, he doesn't make an effort but in the afternoon he is livelier. SLT indicated that the family does not encourage him to be independent and do everything for him, can walk although with a bit of a struggle at times.
- Child I – CP, tries very hard to do everything, extremely chatty, records indicate a rapid improvement in speech over 18 months from no words to well structured sentences (although a bit difficult to understand), mindful of her classmates and tidies them. regularly, tries to correct her teachers on many occasions, can sing in perfect tune, finds it a struggle to breathe to speak or sing words with more than 2 syllables, can walk although with some occasional help.
- Child C – CP, very quiet, enjoys playing with toys that interact, can walk with some help.
- Child A – CP, very intelligent with numerous physical limitations, she uses Clicker 5 to communicate and has started part-time mainstream school. Very talkative but can be unclear, severe problems with both legs and cannot walk independently, she uses her personal laptop for all activities.
- Child T – CP, cannot walk, cannot speak, but extremely intelligent, very good use of eyes – looks sharply at words and pictures to communicate, uses headswitch to play games and writes reports at the end of the day, good sense of humour – teases the teachers using her headswitch and eyepointer, uses yes and no bands on both her wrists to confirm answers, she uses her personal laptop for all activities.

- Their **class teacher was J** for the first half of the day.
 1. They sing a 'hello song' and greet each other, Child R, Child W and Child T used a button to sing their part.
 2. Sing songs to sit up straight, keep their feet together, head straight (each of them an enormous effort).
 3. Child W is late and when he arrives all the children shout and call out for him.
 4. They sing 'if your happy and you know it clap your hands' action song to practice coordination skills, children take turns to chose what they would do. Child T continues to contribute using eyegaze – her personal low-tech device.
 5. They exercise breathing with a story of the wind – Child W cannot do this as he has no control over his muscles
 6. Child T goes on strike and refuses to communicate when she realises that she can't keep up with the rest to contribute towards the song (delay on the teachers part in finding the correct pictures for her).
 7. They split into 2 groups of 3 and go for a bit a physical exercise.
- I joined the group with Child W, Child I and Child A (at this point, all leg support are taken off and the children need more help)
 1. They exercise their toes and feet learning to control simple movements, lifting and keeping their feet in position
 2. They pass a stick learning to use their hands both ways passing it in a circle
 3. They learn to rollover on the mattress onto both sides (Child W is too lazy for this and starts crying and Child I rolls over him and asks him to stop it)
 4. SLT (SLT) comes to work on their listening skills
 5. Children learn to identify animal sounds and imitate them (Child W was very good and making noises and Child I and Child A good and recognising).
 6. They sit on a table to draw. They exercise their hands as all of them have limited hand movements.
 7. The exercise their wrist, hold the hands firm in one place, keep hand flat on the table, practice squeezing the pencil, open hands wide, rub hands together, clench hands, bang on the table, push hands together.
 8. They practice drawing birds feet: around 3 pages of 15-18 birds of different kinds and sizes. They try to keep their lines straight, on top of the existing one. Child A refuses

to do this as she can't do it tidily, Child W uses 2 fingers to hold the pencil and Child I uses 4.

9. They tidy up, have a drink and go to play with little push chairs (to give walking support) with dolls in them – boys didn't seem to mind

- **Specialist Team Manager, (Physical Disability Service, Oxfordshire County Council)**
– a founder member of School, introduced himself and voluntarily provided some useful information. He also directed me towards 3 other professional in the building and organised brief chats with them. He provided me with a good historical overview of the school. School (then for 5-18 year olds) was started almost 25 years ago for children with special needs when there was no computer based AT or AAC. With the introduction of the microchip started their in-house development of ad-hoc AT/AAC devices. A practical approach was taken in helping children use computers. 4-5 years ago as a result of inclusive education the school had to be closed and now they run a pre-school. They also act as an assessment centre for NHS. They have an SEN/ICT (Special Education Needs) support service that evaluates students with special needs from main stream schools and purchase devices for them. They also train support staff. This department he mentioned was a younger version of the THE-Centre and still work with the THE Centre. He also mentioned that the The Centre started at the school and had to move out due to expansion and become a national and later on an international organisation.
- He suggested that I speak to PB or CS who were consultants for ICT and if they were not available to obtain their contact information from AL the administrator. He also recommended the conference 'Communication Matters'.
- Child T cannot go out to play and a new headswitch based game was introduced to Child T by SLT. She only needed instructions once and followed them implicitly. The distance between her head and the two switches was not perfect and at times she couldn't reach. Child T finds it hard to keep her head steady and hence produces unintentional clicks. SLT mentioned that there was a meeting scheduled for Thursday with the The Centre to discuss the positioning of headswitches for Child T. Nevertheless, Child T enjoyed herself selecting animals and animations of her choice and thereafter selecting the animals requested by her AT, SLT and myself. At times she was impatient waiting for the cursor

to move to the animal she wanted. She had 'yes' and 'no' bands in her wrists so that if any of us needed confirmation, she would either look at the wrist or lift it slightly. She also teased us by different choices and laughed (no sound) in a very obvious way.

- SLT informed me that Child A, Child C and Child I and Child W would be attending mainstream schools following summer. Child A already attends mainstream school two days a week. The School follows the National curriculum for these children and provide support both motor and communication even after they have left The School.
- At this point the children were getting ready for their swimming lesson, which was to be followed by lunch.
- Child A and Child T had useful 'communication guides' they carried with them in their wheelchair for anyone who wanted to communicate with them briefly explaining what methods to use.
- The next interview was with **CS (Consultant Advisory Teacher)**

Cath explained that they have divided the work as communication support and motor skills support. Children with motor skill impairment are part of mainstream schools and those with communication support are usually in special schools. Cath works with motor skills and major part of her work is in mainstream schools.

1. Schools refer students to The School eg. Illegible handwriting
2. Hardware needs are assessed eg. Does the student need a spell checker, special mouse, specialised laptop
3. If necessary, based on the hardware choice, the software is selected eg. Predictive typing
4. The hardware and software are purchased by SEN/ICT
5. The TA is trained to assist the child in school
6. The PDT continues to review the progress every 6 months (The disability statement indicates annual review)

7. Support is amended or removed gradually

CS recommended that I speak to SLT2 who works with Special Schools and communication problems.

- I went back to join the children for lunch. They were given support to try and feed themselves as they could not control their hands/arms steadily. Child T and Child R couldn't use their hands and Child W was tube fed. SLT was feeding Child R, who found his right hand easier to control than his left hand. He avoided pointing at anything on his left side. SLT put all his favourite food on the left side and encouraged him to ask for things pointing with his left hand also, which he did. It is Child I's 4th birthday tomorrow and she was busy talking about it. She told all the teachers that they were not invited but her classmates were. She seemed comfortable breathing to speak two syllable words but anything more she had to breathe in-between. Nevertheless, each word and sentence was a struggle and an achievement.
- Following lunch, Child W and Child I remained for speech therapy. Child W was very slow at progressing as he had very limited control over his muscles. In addition he did not make an effort. He could sound vowels but consonants were a challenge. SLT mentioned that the target for the next 3 months was to get him to say 'b' – bus, boy, bear, ball, etc. Child I had improved from no speech to sentences within 18 months. She is very persevering and enthusiastic. She also encouraged Child W to concentrate the sounds. She questioned everything that was taught. She sang the 'wheels on the bus' and insisted that you did not say 'mama's on the bus go chat chat chat' as her mum didn't. Instead she wanted to sing '...ring the bell'. She could sing perfectly in tune although very slowly which added to her breathing conditions. Child I had a conversation with me and Child W responded to what I asked him only in deeds.
- Child I and Child W joined the other children in their artwork time. They were sticking fur onto a huge toll. Child A informed them that it was a friendly toll. Child I enjoyed the activity. Child W was careful not to dirty his hands or apron and did not participate much (SLT explained that not getting their hands dirty was linked with eating difficulties). Child A and Child C enjoyed themselves. Child R couldn't do this

so he was given a bowl of blue paint to splash and exercise his arms. Child T was busy typing a report on her day using SwitchIt – a headswitch device. Using symbols and small words she had written that the weather was sunny, she played a new game, she had fun playing with Child I and Child W. And that she had a bad day. The carers were upset that she wrote this but she was adamant that the report said this and laughed when someone queried this. She printed the report and was taking it home. SLT mentioned that this was Child T's sense of humour and the mother understood that.

- The children tidied up and were getting ready for story time (Three Billy Goats Gruff). As they waited,
- The Child C played interactive guitar, Child A played building blocks with Child T who was strapped on to her seat, Child W played in the sand pit and Child I made play toast and tea for everyone while they waited for Child R to get ready. Child W was introduced to ChatBox an AT device to answer questions for the story time. SLT mentioned that he had very good control over his middle finger in his right hand and could try using this.
- SLT told the story and asked questions continually. Child W answered very well using ChatBox and Child T used her eyegaze on her low-tech vocabulary book. Everyone else tried to shout answers.
- Thereafter the children were ready to go home.

I left to interview **SLT2**. SLT2 works with special schools and addressed communication needs. She was fairly new to the job and had a very different approach. She mentioned that she used numerous conference notes as a guide but used her own method, which was a combination of all of them for assessment.

She looked at (1) Devices: based on need and preferences

(2) Access for devices: hardware, portability and software

and (3) Vocabulary requirements: cognitive abilities such as words and symbols used.

This meeting was very brief but she said that she would post copies of all the conference notes. She also recommended 'Communication Matters' that happens in Leicester and 'AAC

(SIGs) Special Interest Groups' that took place in Oxford 3-4 times a year. She offered to take me on her assessment days on request.

I went back to SLT to have a brief chat. SLT mentioned that they do not group children by CP – Child W being a good example. Besides, looking at diagnoses also contradicts looking at capabilities. They simply look for capabilities such as Child T's eyes and Child W's finger and look for ways of using them. She was willing to test any development/model jointly with SLT from The Centre if we leave it with them over a period of time.

Information for Interviewees

The research aims to design, develop and evaluate an applicable capability model for the development of Assistive Technology for Children with Cerebral Palsy. If a suitable device already exists the model should be able to search through the resources and suggest it as well.

The proposed model with the input of child's Anthropometrics, Capabilities (more than what they can't do) should be processed through existing heuristics, guides and expert knowledge base, search for existing AT devices and check availability of device and suggest guidelines for the development of a nonexistent device

The primary goal of this model is to build assistive devices to suit what these children can do rather than what they cannot do using a dynamic decision support system.

The research currently requires information in identifying:

- What, if any, standard scales of measurement are used to assess this specific special need
- Methods and techniques used, length of typical assessment and specialist equipment and resources required
- What criteria guide the recommendation of specific aids or assistive technologies?
- Success rate of recommendations and choices (technical and emotional satisfaction)
- Review frequency
- Who are the manufacturers of the devices
- How configurable the devices are
- The need to develop the devices or place orders for specialized/customised devices

The researcher would appreciate any sample forms, information packs or leaflets or recommendations for such in this area.

C5 - JMH Interview

Interview with JMH 14th October 2009

Notebook / Diaries:

- Main stream – low tech
- Special school - may not work
- Residential care means the GP is local (only ideal)

In what way is the current situation not ideal?

- Not timely
- Sporadic (irregular)
- Language limitations/incomprehensible
- Too abrupt
- Could be ambiguous
- Dispassionate (parents only)
- Too incessant (professionals)
- Time restrictions (professionals)
- Patronising vs feeling of being patronised when they are not
- Access to internet
- Physical disability of carecircle

What do people think of the proposed solution?

- I don't know what it is
- I don't like social networks
- I don't see how a social network can be used in this situation
- I find social network sites difficult to navigate, see and read. Cannot see the writing on social networks
- I have a disability that makes using a computer difficult
- I have not access to the internet
- This will add to my workload
- I don't have the time to spend/waste at a computer
- I have a busy 'real' social life

- I'm always using social network sites, this would be ideal
- I like social network sites, I'm interested.
- Anything that'll make communication efficient
- I'm not allowed to be on social networks at work
- I use the internet only for work

Base line is to improve the capability by communication

- Current situation is 1-1 towards many - many
- Group discussion people's opinion may not be heard
- Sub categories: hygiene, eating, etc.
- Multimedia with usability and accessibility

Why this was chosen over an interview

- Hard to get data with individual needs
- Difficult to get by questions
- Interviews would be good for the 'stories' and 'case studies'

How important is it for you to have off the record questions about the child?

- Yes very, it is important to be honest
- Can be useful, good to have them
- No everything should be on record and by the book
- Could be different for professionals vs parents
- Levels of privacy?
- Get statistics broadband and wifi
- Should be able to 'visit' history
- Make life easier
- Calendar
- Accessible! social network
- 'Print' option of the social network for professional
- They don't like social workers
 - They are not children at risk!



Research Proposal

ITERATIVE EVALUATION OF SPEECHBUBBLE
- December 2008

Jennifer George

Contents

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1. What is proposed?

The SpeechBubble project aims to provide a searchable website that provides the most relevant details on the hundreds of available assistive devices (AT), and is due to be completed in 2009. This support tool <http://www.ace-centre.org.uk/index.cfm?pageid=6B18152B-3048-7290-FE99D2573C6EAC3E> is proposed to include three main areas for AT: software, talker and vocabulary. The software area deals with access and interface related features while talker addresses input and output methods, and vocabulary looks at complexity and navigation of words.

Previous research by Matching Persons and Technology (MAIR, 2004) states, up to 75-80% of AT devices are being abandoned by their users. The reasons include the technology not being matched well enough to meet the individual's need, little or no training provided to the user and care circle, and members of the care circles not accepting technology.

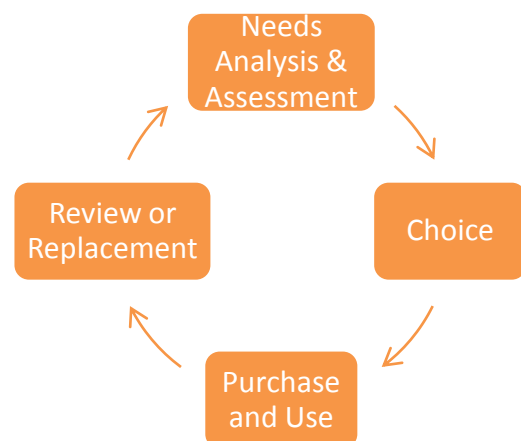


Figure 1 - AT LifeCycle

The life cycle of AT devices would be identified as starting with a child's needs analysis, then selection of AT, purchase and usage, and finally the review or replacement of the AT as per Figure 1.

Members of a care circle may have conflicting opinions in how and what technology should be used meet the needs of a child's communication. Similarly each care circle may vary in their requirements and needs. This proposed research will carry out a series of evaluations of the evolving SpeechBubble system, while investigating ways to extend it through consideration of the needs, wants, concerns and preferences of members of the care circle considering the time at their disposal, technical capability, role values and personal preferences as per Figure 2.

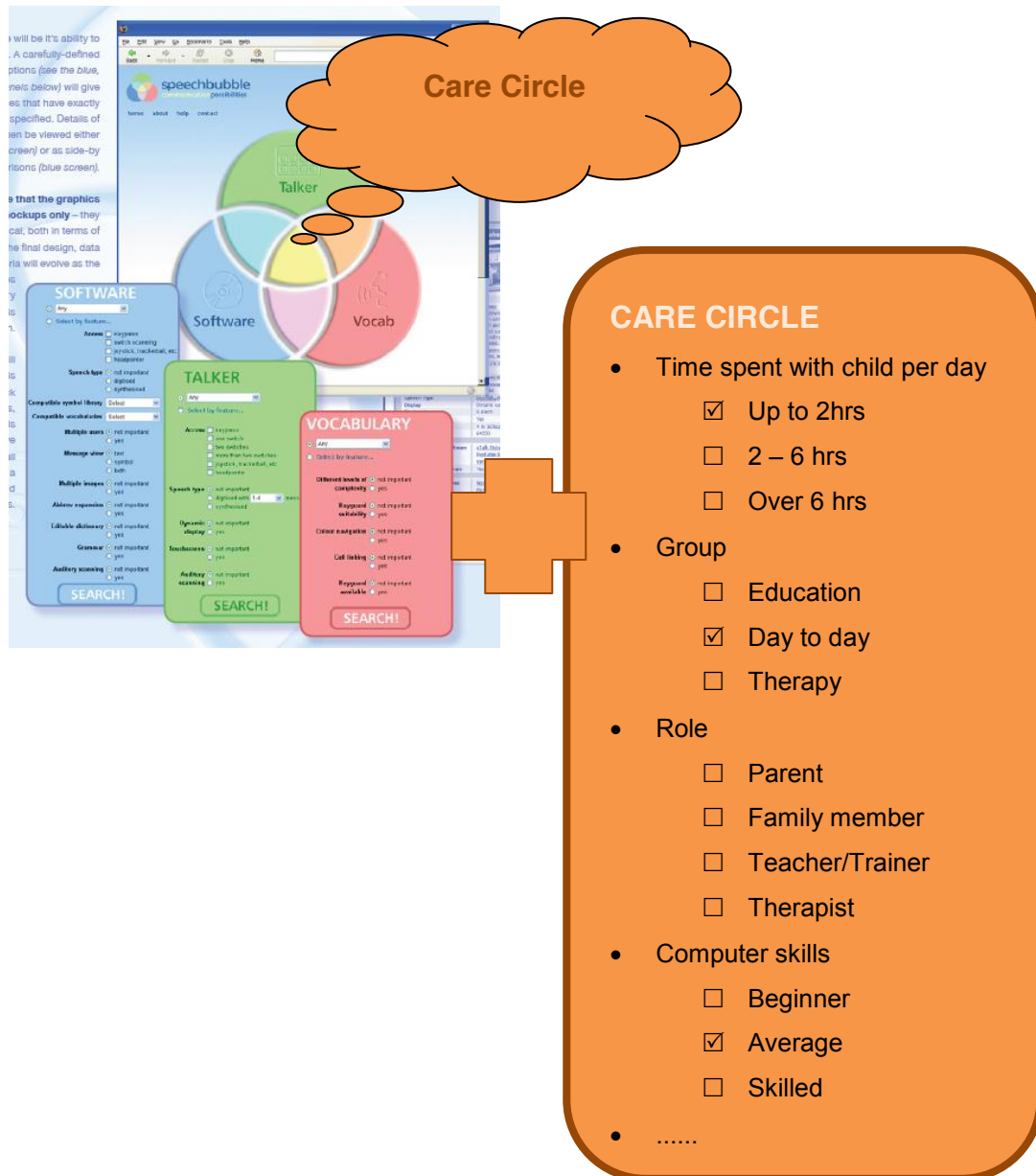


Figure 2 - SpeechBubble Proposal Extract with Indicative Extensions

Members of the care-circle are all involved in the development of a child as parents, carers, teachers, teaching assistants and therapists who constantly use communication devices to communicate with the child. The child learns to communicate using various assistive devices with the various members of the care circle presents a range of challenges that do not arise when using computers at home and at school for able bodied children. Each one of them also has specific needs, wants, challenges, aversions, motivations and values. Multiple stakeholders would provide role-specific evaluation criteria and the key success factors would be

identified. In addition to the three areas that already exist in the SpeechBubble project that are indicated by the blue, green and pink circles together with the corresponding rectangles¹ additional 'care circle' extensions are proposed as indicated by the orange cloud and example profile rectangle.

¹ Image taken from SpeechBubble Project Proposal available online

2. Why is it important?

In the decisions made during a child's development, a team of people including family members, members of staff at school and medical practitioners play important roles, thus creating a care circle. The responsibility of providing the child with suitable assistance and guidance lies with the care circle. Choosing and using the suitable assistive device not only involves a child's physical needs but also specific wants, aversions, motivations and values together with the commitment, capability and availability of the members of the care circle.

A child spends approximately six hours in school. The responsibility of reducing the disability of the child depends greatly, not only on their therapists and teachers, but also on their parents. Parents can accept and understand the child's special need, but they also need to help the child to reduce their disability by increasing independence. Although parents may find it comparatively easier to perform the children's low-level life skill tasks for them, saving time and energy, the children need to be constantly encouraged to carry out low-level tasks themselves with the challenges gradually increased. Parents also appear to be the only constant part of the care circle as the school, teachers, therapists and carers change as the child continues to make progress which also means the specific needs, wants, challenges, aversions, motivations and values also remain dynamic.

3. How could this be done?

The research is to be carried out in three phases. This would consist of an iterative evaluation process of the developing SpeechBubble, accompanied by proposals and implementation of extensions. These are explained in detail throughout this section. Phases 1, 2 and 3 are expected to last for 4 months each.

3.1.Phase 1

The first phase of this research would last for 4 months and looks at the scope required to understand children's use of AT and contrasting different approaches to the choice and selection of AT. This phase of the research aims to understand the care circle's involvement by developing personas that would help in the development of the prototypes and further development of SpeechBubble (Figure 2).

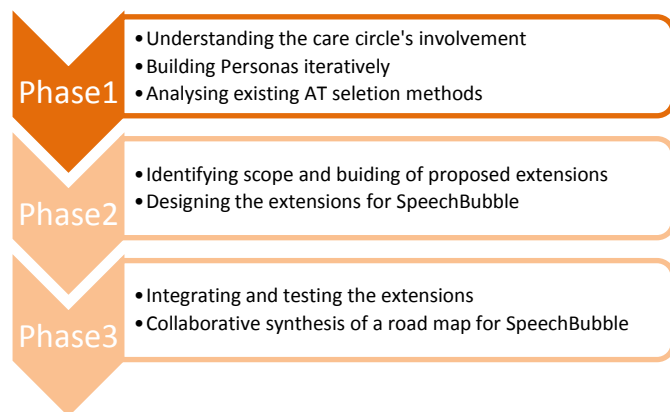


Figure 3-Phase 1

A series of evaluation reports on the existing SpeechBubble project would be provided to ACE during this phase. Evaluation with users would be conducted by way of semi-

structured interviews and user walkthroughs. During the evaluation, information on children who are currently using AT, together with members of their care circle, would be gathered to develop personas². The number of members per care circle is expected to be 5-7. The information may include, age, nature of special need, AT devices currently used, how members of respond to using the communication device with the child, etc. This could be done by way of a questionnaire and/or interviews developed by the researcher with information providers. Information could also be obtained by observations either at the Ace-Centre or Ormerod School³. The interviews with the researcher could take up to 2 hours in total to obtain information

² Personas are profiles or abstract representations of users that help in the design of interfaces (Pruitt and Adlin, 2006) and when exploring relationships between people and technology in the design of Socio-digital systems.

³ Permission to be obtained

for the first time. Following the initial development of personas, feedback from the assessment team at the Ace-Centre could enable identifying the positive and negative attitudes of members of the care circle. For example, whether a parent would rather carry out the task him or herself than bear with the child and encourage independence. This feedback is estimated to take around 1 hour in total every month. This should help further identify the needs of the child and members of the care circle in addition to the requirements stated by them. This iterative process could be carried out either by email or telephone conversations.

Summary: A series of user evaluations of current versions of SpeechBubble would be conducted and reported to Ace Centre. During this time, data needed to develop personas to understand the involvement of members of the care circle would be identified and obtained by way of interviews, questionnaires and emails. Personal and environmental wants and needs relevant to the child and members of the care circle would be identified. This phase would prepare for second phase proposals of extensions to the existing tool to address needs identified in this phase.

3.2.Phase 2

The second phase of the research lasts for 4 months and will design the extensions to SpeechBubble. The personas built in phase 2, together with the opportunities for extension of the SpeechBubble identified in phase 1, would be used to identify possible design extensions. For example, SpeechBubble could be extended to include information on technical capability, time spent with child using the device, role of the care circle member, etc.

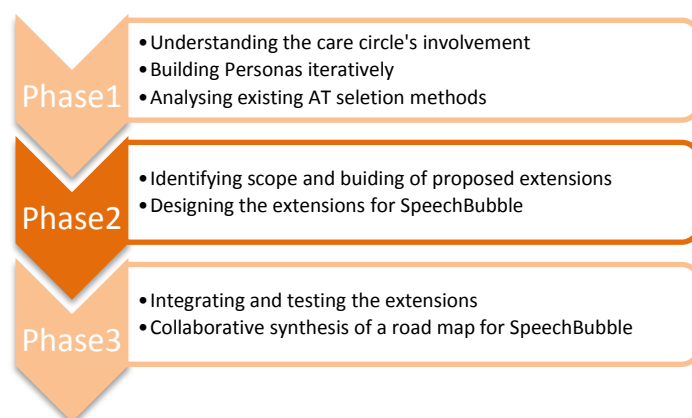


Figure 4 - Phase 2

Paper or low fidelity prototypes would be built, and feedback would be obtained. Walkthroughs of the paper or low fidelity prototypes would be carried out with reference to the personas that represent each member of the care circle. For example at this point it would be possible to identify how a persona would make decisions on the selection and use of an AT device. It will also be possible to identify possible any conflicts in choices or opinions. During this time, feedback from Ace Centre in house experts and the experts evaluating SpeechBubble would also be valuable. This could be done by face-to face meetings, telephone conversations or email. Communication for 1-2 hours every month would be sufficient for this purpose.

At the end of this phase, clear guidelines for the technical implementation of SpeechBubble extensions would be developed in preparation for the final phase of the proposed research.

Summary: Personas from phase 1 would be used to guide design of proposed extensions to phase SpeechBubble. Feedback from experts would be obtained in readiness for implementation in phase 3.

3.3.Phase 3

This phase of the research would last for 4 months and aims to implement the extensions identified and refined in the previous phase. It will then evaluate the SpeechBubble extensions, assessing the extent to which these result in a more comprehensive support system.

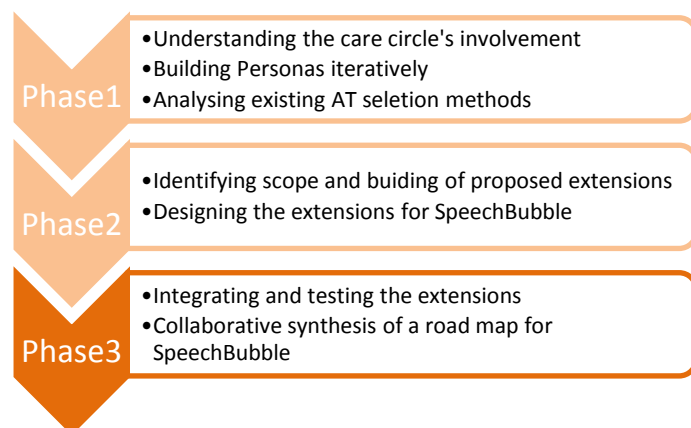


Figure 5 - Phase 3

The opportunity to work with a beta version of current SpeechBubble as the basis for integrating additional features would be needed. This would make it possible to test

the proposed extension with the experts at ACE and if possible a selected number of users. The building of the technical extension could take approximately two – four weeks. If appropriate, ACE's technical expert could collaborate here or the researcher could work independently (if access is granted to a beta version). Advice from in house technical expert during this time would be very beneficial. Testing could be arranged according to the availability of the experts at ACE and this would determine the total contribution to this phase.

At the end of this phase, there would be a tested version of an extended SpeechBubble available for immediate use. This would also be accompanied by an evaluation report. At this point, it would also be possible to propose what changes and improvements could be made to the SpeechBubble Project as a whole in the future.

Summary: Using the proposed extension for which prototypes were designed and tested in phase 2, the extension would be technically integrated into the existing SpeechBubble structure. At the end of this phase, the extended SpeechBubble would be tested and an evaluation report would be presented together with the evaluated extensions.

3.4.Time Table

Phase	Task	Start	End
1	Evaluating and developing Personas	March 2009	June 2009
2	Designing extension	July 2009	October 2009
3	Integrating and testing extension	November 2009	February 2010

Table 1- Project Time Table

3.5.Budget & Finance

There will be no travelling required by staff or clients at Ace Centre for the purpose of this research. Overall, no ancillary expenses are expected to be incurred. If the need for funding arises during the research, this could be reconsidered.

A summary of the nature and duration of requirements together with the upshot at the end of each phase is presented below in Table 2.

	Requirements	Time needed	Benefits for ACE
Phase 1	Information on children who are currently using AT from experts from ACE and members of care circle.	15-30 minutes each for semi-structured interviews and user walkthrough from each member of the care-circle	A series of evaluation reports on the existing SpeechBubble project
		Approximately 1-2 hours in total for the first interview with Ace Centre experts	
		1 hour per month for the following months for user evaluation of SpeechBubble by way of home visits, emails and phone conversations.	
Phase 2	Feedback from Ace Centre's in house experts and the experts evaluating SpeechBubble project.	Monthly communication for 1-2 hours by way of face-to-face meetings, telephone conversations or emails.	Clear design guidelines and paper prototype for extended SpeechBubble
			An evaluation report
Phase 3	The opportunity to work with a Beta version of current SpeechBubble and the person currently responsible for building the project	Occasional communication with the technical experts at ACE over the course of 2 - 4 weeks	A tested version of the extended SpeechBubble
			An evaluation report
	Test time with evaluation team	Approximately 10-15 minutes from each expert at ACE , plus time from users for testing (1 hour sessions)	Proposals for extended SpeechBubble's future (road map)

Table 2 - Summary of requirement

4. Who will benefit?

The Ace Centre would get continuous evaluation reports on the current SpeechBubble project during the first phase. Reports would also be provided during the second phase while the extension to SpeechBubble are being proposed and developed. The evaluated extended SpeechBubble would be given to the Ace Centre to be integrated into the existing search tool at the end of phase 3. The Ace Centre would be acknowledged on all relevant publications by the researcher. The SpeechBubble project would benefit from continuous evaluation for 12 months, with extensions to enhance overall benefits of the project. The members of the assessment team at the Ace Centre would be able to exploit information on members of care circle and their needs, preferences in supporting a child's use of AT.

Parents who spend almost all out of school hours with their children should be more effective in their support for extensive use of devices that they better understand. This should also help them make AT choices considering their additional family commitments, jobs, existing technical skills and willingness to learn new technology, thus considering environmental and personal factors. This would also be beneficial if they are independently looking for devices without a formal assessment.

Class teachers who are involved in inclusive education will be able to communicate with their students who use AT more comfortably. In a class where some children use AT devices that are also individualistic, when an AT device that enhances communication is used, this would support the teacher in running the class more smoothly. Teaching assistants who spend almost all day with children will be able to choose devices that would be most suitable between them and the child making their communication more effective. Other members of the care circle who spend comparatively less time with the child such as the speech and physiotherapists will be able to make more effective use of the limited time at their disposal if the most suitable communication device was selected.

Most of all, children will get the best of their care circle across different situations and

environments, when they are more comfortable and happier with the devices that are used to communicate with members of the care circle.

The research would be part of a PhD thesis at University of Sunderland in the analysis of situating of assistive technology for young children within worthwhile socio-digital systems for caring and personal development.

21st July 2009

11.30am – 1.00pm

OT1 (Occupational Therapist – Head of Assessment)

OT2 (Occupational Therapist) - joined us for specific discussion on social networking

I introduced myself, the Research and purpose of interview

OT1 introduced the new structure of assessments. Two methods:

- (1) Service Level Agreement (SLA) with the Local Authority & NHS that comes with funding and package of care
- (2) Referred by the Local Authority but self funded. They require a quote prior to assessment (which they are unhappy with as it is case specific). They offer their 4 options (They are not on their updated site - £700 – £4,800) and ask client to choose or depending on the funds at disposal they tailor the package according to the need.

1) What form of regular support do you provide for families with special needs children?

- Phone
- Email
- Chatterbox Club
- Onsite training
- Annual reviews

2)

(a) Do you currently have a forum, physical or virtual social network or support groups?

(b) What key activities do the support groups provide?

- Offer follow ups (quite expensive)
- Initial support for care circle is provided on the day of assessment (included in fee)
- People can phone in or email anytime (included in fee)
- Invited to attend the Chatterbox Club meeting twice a year (included in fee)
 - Peer networking for parents, siblings, children (they don't meet similar children once they start mainstream schools)
- Use google groups (included in fee)

- Virtual support from AT/AAC service providers but onsite training for customizing is provided by THE Centre (included in fee)
- They have attempted teleconferencing previously (5 years ago) not entirely successful.

3) What are the current challenges with these support groups?

- All care circles Birmingham downwards area required to get to Oxford which is inconvenient
- Priorities
- Gravity of need wears down
- They attend the groups only when they have an immediate need and they may have to wait for up to 6 months for the next one

At this point OT2 joined us.

(Show paper prototypes here)

4) Do you think a social network could solve or help solve challenges in: communication, updates, travel and expenses?

- Yes
- Support and follow up are immediate NEEDS

5) Do you see social networks addressing any other challenges?

- Will not be replacement for main assessments but could be beneficial for post assessment which is quite expensive
- They could be provided with more accurate support
- Could be advised on funding
- Support during transitions between schools
- Educational tribunal support

6) Are there any restrictions on being part of a secure social network?

- NHS will be the biggest nightmare
- Care circle is fairly open – but requires need for ‘off the record’ conversations

- 7) In your opinion, how capable are the members of care circle in using social networks?
- Capability will not be an issue if it is usable, willingness would be a challenge for some parents, especially those with more than one child
- 8) How often do you think people will be able to use social networks?
- Need based – without obligation
 - The Centre is currently discussing needs for a virtual environment.

(Cost and benefits)

- The Centre is happy to post questionnaire for user needs analysis on their google group or circulate during next Chatterbox club (latter is recommended due to numbers)
- Contact PO and OT2 with and prototypes or ideas, they will appreciate my ‘free’ service

Additional Recommended Reading:

BETA (2005) – Communication Aids Project Model for Referral Process. This project was pioneered by Mick Thomas

Karen Erickson – ISAAC Conference (2008) in Montreal Online System for Collecting Referrals

Thesis by Mick Donaghan from The Centre – has a intranet/cut down internet based database used for assessments

Family Members

1.1 Question 1

Question No.	1
Question	Depending on the age of the child or adult you care for, the communication purposes and needs will differ. To help us provide the most appropriate solution, please write the age of the said child or adult. The age of child or adult I care for is:
Purpose	Demographics
Assumptions	6. Age of cared for individual is 0-16
Missing Information	F - Demographics, including IT access, of care circle
Response	20, 20, 10, 6, 6
Conclusion	The age range of the child or adult mentioned by the families narrow the range from 0-100+ mentioned by the professionals. Logically there need be no restriction on how old the person cared for should be but for the purpose of appropriateness of content, individuals in formal education are considered. This is not within the assumed age range but includes those with delayed learning as well.




1.2 Question 2.1

Question No.	2.1
Question	Write the number of family members, relatives and friends who are involved with your child's progress:
Purpose	Demographics
Assumptions	5. Care circle membership is between 2 and 7
Missing Information	F - Demographics, including IT access, of care circle
Response	2,3,3,10,2



Conclusion	<p>Family member's view of the care circle members is smaller than the professionals.</p> <p>Visually, if the design solution could show what job titles are part of the care circle, the family members may be encouraged to invite others who are part of the care circle to join.</p>	
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1.3 Question 2.2

Question No.	2.2	
Question	Please list the relationships. Eg. Dad, aunt, grandmother, family-friend, etc.	
Purpose	Demographics	
Assumptions	5. Care circle membership is between 2 and 7	
Missing Information	F - Demographics, including IT access, of care circle	
Response	<p>Daddy and Mummy <u>Only</u></p> <p>Mother, Father, Me (sister)</p> <p>Parents, Siblings, Grandparents, Relatives, Carers</p> <p>Mother, Father, Sister, Grandmothers (2) Grandfather (2)</p> <p>Step-Grandfather(1)Cousins(2)</p> <p>Mother and Father</p>	
Conclusion	<p>Two members of the care circle jointly completed a single form and it is interesting to note that although the sister considers herself involved in the decision making, the mother's view is that 'only' herself and her husband make decision. One form was completed by both parents. It may be useful to consider a single account named 'parents' if they don't want to have separate accounts. It is also interesting to note that although the professionals include family members as part of the care circle, the family members haven't included any. This is an interesting design challenge to see if family involvement and care circle size could be improved.</p>	

1.4 Question 2.3

Question No.	2.3
Question	What is your relationship to the child or adult you care for?
Purpose	Demographics
Assumptions	N/A
Missing Information	F - Demographics, including IT access, of care circle
Response	Mother – 2 Sister Parents Grandmother
Conclusion	This was largely influenced by participant sample and clarifies the perspective of the responses.




1.5 Question 3

Question No.	3
Question	Which of the following features and functions of the internet do you use?
Purpose	Current situation
Assumptions	3. The care circle members own a computer and access the internet; 4. That social networking is a viable solution;
Missing Information	F - Demographics, including IT access, of care circle
Response	E-mail - 5 Forums or Discussion groups - 2 Chat (text or voice) - 2 Social networks – 2
Conclusion	All of them use email however none of them use blogs and video messaging. With only 2 of them using social networks, there may be a need for some persuasion needed to get them to use it. Interestingly, some parents who do not use social




	networks seem to use features that would be part of a social network. This might simply be a matter of calling a social network something else.	
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1.6 Question 4

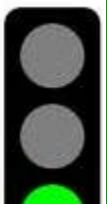
Question No.	4	
Question	You may be using various media to communicate with other family members, carers, professionals from schools and support organisations. This could give you the needed flexibility and at the same time complicate things when all those you would like to consult are unavailable or have to duplicate information when using various media.	
Purpose	Current situation-Evaluation	
Assumptions	<p>1 (c) Assessment is usually only once a year;</p> <p>1 (d) Child may be unable to communicate problems between professionals and family members;</p> <p>1 (e) Multiple methods of communication are independently accessed, unstructured and uncoordinated;</p> <p>1 (g) It is impossible to provide technical support on AT devices;</p> <p>1 (h) Therapy and help is offered onsite (location) only;</p> <p>1 (i) Need to search various website and databases to find relevant information on schools and opportunities and still not have reliable answers;</p> <p>1 (j) Information pack is obtained only in hard copy;</p> <p>2. There is a need for frequent communication within care circles</p> <p>3. The care circle members own a computer and access the internet;</p> <p>4. That social networking is a viable solution;</p>	
Missing Information	D- What methods of communication are used, and which are preferred, and when	

Response	<p>Telephone 2 use very frequently; 1 frequently; 2 occasionally</p> <p>SMS: 1 very frequently; 2 never; 1 rarely;</p> <p>Email: 2 very frequently; 2 occasionally; 1 rarely;</p> <p>Letter: 1 very frequently; 2 occasionally; 2 rarely;</p> <p>Child's homework book: 4 very frequently; 1 never;</p> <p>Events: 1 very frequently; 2 occasionally; 1 never; 1 did not answer</p> <p>Onsite training: 4 rarely; 1 never; 1 did not answer</p> <p>Social network: 2 occasionally; 2 never; 1 did not answer</p> <p>Online forums and chats: 1 frequently; 2 rarely; 1 never; 1 did not answer</p> <p>1 other options</p>	
Conclusion	<p>Some questions have been left unanswered and other answers are influenced by the fact that they all care for someone in formal education. It is clear that all family members regularly use different types of online and offline communication methods to keep in touch about the individual concerned. However most of the methods used are one to one or one to few communications which the other care circle members would probably be unaware of. It is also interesting to note that there is more reliance on the homework book compared to the professionals.</p> <p>In the design solution it is important to be able to select entire care circle or select or deselect specific members of the care circle to share content. You should also be able to add further members during the discussion later on. For members of the care circle who would only use off line methods, it should be possible to add them as offline participants but print off a copy to send by post. This option should be given only to the official carer as this could involve protected personal information i.e. postal address.</p>	

1.7 Question 5

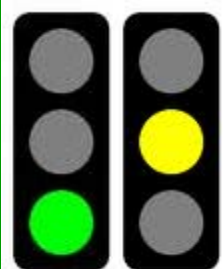
Question No.	5	
Question	Select how likely are you to access the internet or any other network for a solution for answers to questions you may have about the child or adult you care for?	
Purpose	Current situation-Evaluation	
Assumptions	1 (i) Need to search various website and databases to find relevant information on schools and opportunities and still not have reliable answers; 2. There is a need for frequent communication within care circles 3. The care circle members own a computer and access the internet; 4. That social networking is a viable solution;	
Missing Information	D- What methods of communication are used, and which are preferred, and when	
Response	2 very likely; 2 likely; 1 unlikely	
Conclusion	Except for 1 participant, others appear to be comfortable looking for information online. Through a post questionnaire communication with the participant, it became clear that the participant needs more confidence in using the internet and if she is provided with a direct URL via email, she is happy to look for information within the site. This could be a matter of reassurance but is an interesting challenge. A technical consideration of being able to share a URL via email could also be considered, which is not an insurmountable barrier.	

1.8 Question 6

Question No.	6	
Question	Peer networking with other families or professionals may be beneficial for both practical and emotional support members of the care circle. Select to show how important you consider	


	communicating with other care circles	
Purpose	Current situation - opinion	
Assumptions	1 (a) Time and distance limitations prevent all members of care circle from participating in all meetings; 1 (b) Only dedicated professionals can answer queries even when peers/other care circle members might know the answer but need to wait. But, this is a major time and financial investment from professionals; 4. That social networking is a viable solution;	
Missing Information	A- What is good about the current situation B- Definitive list of what is not ideal about the current information	
Response	3 very important; 2 important	
Conclusion	This response is 100% positive and confirms that it is important for members of the care circle to support each other.	

1.9 Question 7

Question No.	7	
Question	With the variety of ways to communicate at your disposal, you may find they are either used to it highest potential or inefficiently. Select how you would judge the current ways of communication with professionals and family members involved with the child or adult you care for?	
Purpose	Current situation - opinion	
Assumptions	1 (e) Multiple methods of communication are independently accessed, unstructured and uncoordinated; 1 (f) Children are treated as one of many 'patients' or isolated; 4. That social networking is a viable solution;	


Missing Information	A- What is good about the current situation B- Definitive list of what is not ideal about the current information	
Response	4 Good; 1 poor	
Conclusion	Next to 6, this response looks negative or amber. If not it is largely positive and green. Most family members appear to be happy with the existing solutions. As family members, they are more concerned about information than the method itself. The negative response could be due to the carer feeling the professional's treating her child as one of many 'patients'; However the proposed design solution should improve the current solution.	

1.10 Question 8


Question No.	8	
Question	In assessing the current situation with communication options, there may be varied opinions on the various factors that make communication effective. Select how much you agree with the following qualities of the current communication options regarding the individuals you care for.	
Purpose	Current situation - opinion	
Assumptions	1 (e) Multiple methods of communication are independently accessed, unstructured and uncoordinated; 1 (f) Children are treated as one of many 'patients' or isolated; 4. That social networking is a viable solution;	
Missing Information	A- What is good about the current situation B- Definitive list of what is not ideal about the current information	
Response	Timely - 4 agree; 1 neutral; Helpful - 4 agree; 1 no answer Flexibility of alternatives - 1 Strongly agree; 4 agree;	

	Regular - 1 Strongly agree; 3 agree; 1 neutral; Empathetic - 4 agree; 1 disagree; 2 Other options	
Conclusion	Except for one disagreement, 2 neutrals and 1 no answer, the family members seem to predominantly agree on the positive qualities. This situation could clearly be improved. An effective design solution should improve the current situation to more 'Strongly Agrees'.	

1.11 Question 9


Question No.	9	
Question	From the previous question please write 2-3 qualities you would like to keep at least as good as they are currently.	
Purpose	Current situation - opinion	
Assumptions	4. That social networking is a viable solution;	
Missing Information	A- What is good about the current situation	
Response	Helpful, Timely Family, School, Carers Regular, Flexibility of alternatives Regular and Helpful 1 didn't answer	
Conclusion	Green – refer to 8 These are to be absolute requirements for artifact features	

1.12 Question 10

Question No.	10	
Question	Select to show how much you agree with the following qualities of the current communication options regarding the child or adult you care for?	
Purpose	Current situation - opinion	
Assumptions	1 (a) Time and distance limitations prevent all members of	


	<p>care circle from participating in all meetings;</p> <p>1 (b) Only dedicated professionals can answer queries even when peers/other care circle members might know the answer but need to wait. But, this is a major time and financial investment from professionals;</p> <p>1 (d) Child may be unable to communicate problems between professionals and family members;</p> <p>1 (e) Multiple methods of communication are independently accessed, unstructured and uncoordinated;</p> <p>1 (f) Children are treated as one of many 'patients' or isolated It is impossible to provide technical support on AT devices;</p> <p>1 (g) It is impossible to provide technical support on AT devices;</p> <p>4. That social networking is a viable solution;</p>	
Missing Information	B-Definitive list of what is not ideal about the current information	
Response	<p>Reluctant - 2 agree; 1 neutral; 1 no answer; 1 disagree;</p> <p>Ambiguous - 1 neutral; 2 no answer; 2 disagree;</p> <p>Abrupt - 2 no answer; 3 disagree;</p> <p>Patronising - 2 no answer; 3 disagree;</p> <p>Other – 2</p>	
Conclusion	<p>The responses provide some useful points for what to avoid in the UX design.</p> <p>Even though questions 7 and 8 appear to give a comparatively positive view of the current situation, responses from question 10 clearly shows that there are many points for improvement and clearly avoid when designing the solution.</p>	

1.13 Question 11

Question No.	11	
Question	From the above please write the 2-3 most important issues on	


	communication quality that you would like dealt in order of priority because of difficulties now or in the past.	
Purpose	Current situation - opinion	
Assumptions	<p>1 (a) Time and distance limitations prevent all members of care circle from participating in all meetings;</p> <p>1 (b) Only dedicated professionals can answer queries even when peers/other care circle members might know the answer but need to wait. But, this is a major time and financial investment from professionals;</p> <p>1 (d) Child may be unable to communicate problems between professionals and family members;</p> <p>1 (e) Multiple methods of communication are independently accessed, unstructured and uncoordinated;</p> <p>1 (f) Children are treated as one of many 'patients' or isolated</p> <p>1 (g) It is impossible to provide technical support on AT devices;</p> <p>4. That social networking is a viable solution;</p>	
Missing Information	B-Definitive list of what is not ideal about the current information	
Response	<p>Ambiguity, Reluctance</p> <p>Services are reluctant at times, Not reliable at times, Support services are withdrawn</p> <p>N/A</p> <p>Ambiguous</p> <p>Lack of support, Health problems, Not enough Understanding</p>	
Conclusion	The responses clearly prioritise points that need to be considered in the features of the artefact.	

1.14 Question 12

Question No.	12	
Question	There may be family members who wish to participate in the discussions and decision-making regarding a child, but are unable to do so for various reasons.	


Purpose	Current situation - evaluation	
Assumptions	1 (a) Time and distance limitations prevent all members of care circle from participating in all meetings; 1 (b) Only dedicated professionals can answer queries even when peers/other care circle members might know the answer but need to wait. But, this is a major time and financial investment from professionals;	
Missing Information	C-Definitive list of what could be better about the current information	
Response	Language limitations of family members-2 Motor or Physical disabilities of family members Computer competency challenges of family members-2 3 - none	
Conclusion	Deep Amber The 3 points mentioned are all about the same family member and from two care circle members of the same child. The mother has both English language, IT skills barriers and is also elderly. Good usability and accessibility could potentially reduce these challenges and if the social network is successful, other translations could also be considered.	

1.15 Question 13


Question No.	13	
Question	Select to indicate how frequently you access the Internet.	
Purpose	Current situation-Demographics	
Assumptions	3. The care circle members own a computer and access the internet; 4. That social networking is a viable solution;	
Missing Information	F-Demographics, including IT access, of care circle	
Response	3 Several times a day 1 Every few days	

	1 Once a day	
Conclusion	Overall this is an encouraging response as all family members appear to check their emails atleast once a day. However, the scale may have been flawed with 'much' placed below 'several'. It is not possible to say if the participants looked at where they were visually placed or marked according to what it read.	

1.16 Question 14


Question No.	14	
Question	There may be times when you feel that verbal communication is preferred over written ones that go on record depending on the nature of the matter. How important is it for you to have off the record conversations about the individuals you care for?	
Purpose	Ideal situation	
Assumptions	2. There is a need for frequent communication within care circles 4. That social networking is a viable solution;	
Missing Information	D- What methods of communication are used, and which are preferred, and when	
Response	4 Very important, we need to be as open as possible 1 Fairly important, an informal chat can be useful	
Conclusion	All family members believe off the record conversations are useful or very important. Design options should consider text, voice or video chat options where records are not held.	

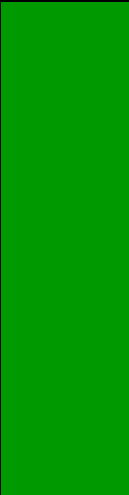
1.17 Question 15

Question No.	15	
Question	Online social media could potentially offer the following solutions in a single website. Which of the following subjects do you discuss with members of the care circle?	
Purpose	Ideal situation – Opinion	
Assumptions	4. That social networking is a viable solution;	


Missing Information	E- Opinion on Social networking	
Response	Education - 5 Therapy - 4 Assessments - 4 Care & Hygiene - 4 Entertainment - 3 Assistive technology	
Conclusion	The responses clearly list the information in demand in order of priority. This will be taken into account when adding features to the interface.	

1.18 Question 16


Question No.	16	
Question	Online social media could potentially offer the following solutions in a single website. Which of the following functions and features would you like the website to have?	
Purpose	Ideal situation – Opinion	
Assumptions	4. That social networking is a viable solution;	
Missing Information	E- Opinion on Social networking	
Response	Funding assistance - 4 Feedback on queries about your child - 3 Option to choose the information to be shared with each member of care circle - 3 Progress updates for/on your child - 2 Should be able to view previous records 2 Audio/Video chats - 2 Forums or discussions Being able to print copies of discussions - 2 Calendar Follow up online assessments	

	Technical support for assistive technologies	
Conclusion	Similar to the professionals, more features that the users would like to use are clearly listed in order of priority. The suggestions clearly show that some of the features requested are mainly used in e-learning environments. This may be a matter of renaming the proposed support site. This also suggests that the priority of family members do not match the professionals. If possible, the order should be different or customisable to the family members.	

1.19 Question 17

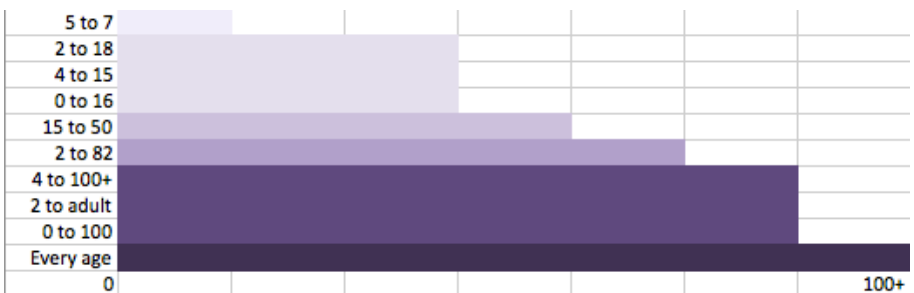
Question No.	17	
Question	If the proposed website was to be a form of social network (such as Facebook, Bebo, LinkedIn, etc.) but specific to support your child's development, you may have various opinions and concerns. What concerns would you have if an online network was launched to address the needs of communication?	
Purpose	Ideal situation – Opinion/negative	
Assumptions	4. That social networking is a viable solution;	
Missing Information	E- Opinion on Social networking	
Response	Time demands for participation and use - 2 Timeliness and reliability of response Privacy and Security – 3	
Conclusion	Amber by nature but similar to professionals in most choices. There is no family member without concerns. This may be due to the participants of this questionnaire being unaware of the potential challenges. It important that this UX challenge is met by providing the participants with an assurance that this would be secure, would make their time management more efficient.	

1.20 Question 18

Question No.	18	
Question	We are currently investigating the possibility of a social network that hopes to improve the current communication and networking strategies for children. Would you be interested in supporting this investigation by evaluating the interface in development at various stages? It would take approximately three 45 minute sessions over a year.	
Purpose	Future evaluations	
Assumptions	4. That social networking is a viable solution;	
Missing Information	N/A	
Response	3 out of 5 participants agreed to take part in future questionnaires.	
Conclusion	Amber Most participants have agreed to participate in future studies however it will be useful to get more participants.	


Professionals

1.1 Question 1


Question No.	1																						
Question	Depending on the age of the child or adult you care for, the communication purposes and needs will differ. To help us provide the most appropriate solution, please write the range of age of the children or adults you work with. The age of children or adults I care for range fromto.....																						
Purpose	Demographics																						
Assumptions	6. Age of cared for individual is 0-16																						
Missing Information	F - Demographics, including IT access, of care circle																						
Response	<p>2 to 82</p> <p>0 to 100</p> <p>Every age</p> <p>2 years to adult</p> <p>15 to 50</p> <p>2 to 18</p> <p>4 to 15</p> <p>4 to 100+</p> <p>5 to 7</p> <p>0 to 16</p>  <table border="1"> <thead> <tr> <th>Age Range</th> <th>Frequency (Number of Participants)</th> </tr> </thead> <tbody> <tr> <td>5 to 7</td> <td>4</td> </tr> <tr> <td>2 to 18</td> <td>10</td> </tr> <tr> <td>4 to 15</td> <td>10</td> </tr> <tr> <td>0 to 16</td> <td>10</td> </tr> <tr> <td>15 to 50</td> <td>10</td> </tr> <tr> <td>2 to 82</td> <td>10</td> </tr> <tr> <td>4 to 100+</td> <td>10</td> </tr> <tr> <td>2 to adult</td> <td>10</td> </tr> <tr> <td>0 to 100</td> <td>10</td> </tr> <tr> <td>Every age</td> <td>10</td> </tr> </tbody> </table>	Age Range	Frequency (Number of Participants)	5 to 7	4	2 to 18	10	4 to 15	10	0 to 16	10	15 to 50	10	2 to 82	10	4 to 100+	10	2 to adult	10	0 to 100	10	Every age	10
Age Range	Frequency (Number of Participants)																						
5 to 7	4																						
2 to 18	10																						
4 to 15	10																						
0 to 16	10																						
15 to 50	10																						
2 to 82	10																						
4 to 100+	10																						
2 to adult	10																						
0 to 100	10																						
Every age	10																						
Conclusion	Four participants had an upper age limit between 5 and 18 but this was mainly due to the speciality of their responsibilities. Seven of them had lower limits ranging from 2 and 15. The																						

	<p>overall age ranged from 0 to 100+.</p> <p>Some assessment centres assess children under the age of 16 for the purpose of education only. While GPs usually don't have special age groups. This poses a challenge for inclusiveness in the design solution.</p>	
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1.2 Question 2.1

Question No.	2.1	
Question	The number of professionals who are involved with an individual's progress ranges from:to	
Purpose	Demographic	
Assumptions	5. Care circle membership is between 2 and 7	
Missing Information	F - Demographics, including IT access, of care circle	
Response	1 to 3 5 to 15 Varies 3 to 6 2 to 6 2 to 3 4 to 10 6 to 10 1 to 5	
Conclusion	Members of care circle range from 1 to 15. This is an interesting discovery, as the professionals believe they are already part of a large care circle.	


1.3 Question 2.2

Question No.	2.2	
Question	Please write their roles. Eg. Speech therapist, carer, teaching	

	assistant
Purpose	Demographic
Assumptions	5. Care circle membership is between 2 and 7
Missing Information	F - Demographics, including IT access, of care circle
Response	<p>The following job descriptions have been listed by the professionals</p> <p>Speech and Language Therapist/ Speech Pathologist (8)</p> <p>Teacher/Special Education Teacher (8)</p> <p>Occupational Therapist (8)</p> <p>Physician coordinates/GP/Paediatrician (7)</p> <p>Psycomotrician (4)</p> <p>Social Worker/Health visitor (4)</p> <p>Nurse -Practise/District/Hospital (4)</p> <p>Carer (3)</p> <p>Physical Therapist (3)</p> <p>Psychologist (3)</p> <p>Child and Adolescent Mental Health Services/Primary Care Trust/Autistic Advisory Service (3)</p> <p>Family Caretaker including Mother, Father, siblings, relatives (2)</p> <p>Educational Interventionist</p> <p>Physical Education Teacher</p> <p>Grandparents</p> <p>Doctor (neurologist, orthopaedist)</p> <p>Nutritionist</p> <p>Technologist</p> <p>Health Care Assistant</p> <p>Practice Manager</p> <p>Learning Disabilities Team</p>
Conclusion	The responses have been arranged according to frequency of job description mentioned by the participant. New job


	<p>descriptions that have not been thought of or assumed have been listed and the number of care circle members listed is also more than the assumption.</p> <p>This is a clear green light and stronger understanding of the complexity of care circles. Therefore, circles or groups that represent them should be created.</p> <p>From the design perspective, pre-defined roles could be included to select when creating the profile and if it is not listed, the user should be able to define their own job description.</p>	
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1.4 Question 2.3


Question No.	2.3	
Question	What is your role or job designation within the care circle?	
Purpose	Demographic	
Assumptions	N/A	
Missing Information	F - Demographics, including IT access, of care circle	
Response	GP X 2 TA Swimming teacher Psychomotorist Project manager SLT Director of Assessment Swallowing evaluation specialist OT	
Conclusion	<p>This list may be biased as the participants are an opportunity sample.</p> <p>Have a predefined role for peoples and have a 'self define</p>	

	option' (Same as 2.2)	
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1.5 Question 3

Question No.	3	
Question	Which of the following features and functions of the internet do you use?	
Purpose	To understand current situation	
Assumptions	3. The care circle members own a computer and access the internet; 4. That social networking is a viable solution;	
Missing Information	F - Demographics, including IT access, of care circle	
Response	All of them use Email 6 participants use chat 5 of them use Forums or discussion groups 5 of them use Social Networks 4 of them use Blogs 3 participants use video messaging Other: AAC and speech, Skype, games/tools/materials, Search engines, Educational	
Conclusion	This response confirms that all participants have access to and regularly use a computer and the internet.	


1.6 Question 4

Question No.	4	
Question	You may be using various media to communicate with parents, carers, other professionals in schools and support organisations. This could give you the needed flexibility and at the same time complicate things when all those you would like to consult are unavailable or have to duplicate information when using various media.	
Purpose	Current situation-Evaluation	

Assumptions	<p>1 (c) Assessment is usually only once a year;</p> <p>1 (d) Child may be unable to communicate problems between professionals and family members;</p> <p>1 (e) Multiple methods of communication are independently accessed, unstructured and uncoordinated;</p> <p>1 (g) It is impossible to provide technical support on AT devices;</p> <p>1 (h) Therapy and help is offered onsite (location) only;</p> <p>1 (i) Need to search various website and databases to find relevant information on schools and opportunities and still not have reliable answers;</p> <p>1 (j) Information pack is obtained only in hard copy;</p> <p>2. There is a need for frequent communication within care circles</p> <p>3. The care circle members own a computer and access the internet;</p> <p>4. That social networking is a viable solution;</p>
Missing Information	D- What methods of communication are used, and which are preferred, and when
Response	<p>Telephone: 8 very frequently; 2 occasionally</p> <p>SMS: 5 very frequently; 2 frequently; 2 never; 1 rarely;</p> <p>Email: 7 very frequently; 1 frequently; 1 rarely; 1 never;</p> <p>Letter: 5 frequently; 3 occasionally; 2 very frequently;</p> <p>Child's homework book: 4 never; 2 very frequently; 2 frequently; 2 - did not answer</p> <p>Events: 3 very frequently; 2 frequently; 2 occasionally; 2 rarely; 1 did not response</p> <p>Onsite training: 3 frequently; 2 very frequently; 2 occasionally; 1 rarely; 2 did not answer</p> <p>Social network: 4 very frequently; 3 occasionally; 2 never; 1 did not answer</p> <p>Online forums and chats: 3 frequently; 1 very frequently; 2 occasionally; 3 never; 1 did not answer</p>


	4-Other options	
Conclusion	<p>Some questions have been left unanswered and other answers are influenced by the fact that the professional is not involved in an education setting. It is clear that all professionals regularly use different types of online and offline communication methods to keep in touch about the individual concerned. However most of the methods used are one to one or one to few communications which the other care circle members would probably be unaware of.</p> <p>In the design solution it is important to be able to select entire care circle or select or deselect specific members of the care circle to share content. You should also be able to add further members during the discussion later on. For members of the care circle who would only use off line methods, it should be possible to add them as offline participants but print off a copy to send by post. This option should be given only to the official carer as this could involve protected personal information i.e. postal address.</p>	

1.7 Question 5

Question No.	5	
Question	Select to indicate how likely are you to access the internet or any other network for a solution for answers to questions you may have about the children or adults you care for?	
Purpose	Current Situation-Evaluation	
Assumptions	<p>1 (i) Need to search various website and databases to find relevant information on schools and opportunities and still not have reliable answers;</p> <p>2. There is a need for frequent communication within care circles;</p> <p>3. The care circle members own a computer and access the</p>	


	internet; 4. That social networking is a viable solution;	
Missing Information	D- What methods of communication are used, and which are preferred, and when	
Response	7 – very likely 2 – likely 1 – neutral	
Conclusion	The fact that no participants selected either unlikely or very unlikely with a majority of the very likely indicates that all professionals would potentially look online for information.	

1.8 Question 6


Question No.	6	
Question	Peer networking with other families or professionals may be beneficial for both practical and emotional support members of the care circle. Select to show how important you consider communicating with other care circles is.	
Purpose	Current situation - opinion	
Assumptions	1 (a) Time and distance limitations prevent all members of care circle from participating in all meetings; 1 (b) Only dedicated professionals can answer queries even when peers/other care circle members might know the answer but need to wait. But, this is a major time and financial investment from professionals; 4. That social networking is a viable solution;	
Missing Information	A- What is good about the current situation B- Definitive list of what is not ideal about the current information	
Response	9- very important 1-important	
Conclusion	This response is 100% positive and confirms that it is important for members of the care circle to support each	

	other.	
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1.9 Question 7


Question No.	7	
Question	With the variety of ways to communicate at your disposal, you may find they are either used to it highest potential or inefficiently. Select how you would judge the current ways of communication with professionals and family members involved with the children or adults you care for?	
Purpose	Current situation-opinion	
Assumptions	1 (e) Multiple methods of communication are independently accessed, unstructured and uncoordinated; 1 (f) Children are treated as one of many 'patients' or isolated; 4. That social networking is a viable solution;	
Missing Information	A- What is good about the current situation B- Definitive list of what is not ideal about the current information	
Response	2 – very good 5 - good 2 – ok 1 – no answer	
Conclusion	Most professionals appear to be happy with the existing solutions. This could be due to them making the maximum use of the existing communication options. This could also be due to each 'patient' being one of many.	


1.10 Question 8

Question No.	8	
Question	In assessing the current situation with communication options, there may be varied opinions on the various factors that make communication effective. Select how much you agree with the following qualities of the current communication options regarding the individuals you care for.	


Purpose	Current Situation-Evaluation	
Assumptions	1 (e) Multiple methods of communication are independently accessed, unstructured and uncoordinated; 1 (f) Children are treated as one of many 'patients' or isolated; That social networking is a viable solution;	
Missing Information	A- What is good about the current situation B- Definitive list of what is not ideal about the current information	
Response	Timely – 4 Strongly agree; 4 agree; 1 neutral; 1 no answer Helpful - 3 Strongly agree; 6 agree; 1 no answer Flexibility of alternatives - 2 Strongly agree; 5 agree; 1 neutral; 1 disagree; 1 no answer Regular - 1 Strongly agree; 7 agree; 1 neutral; 1 no answer Empathetic - 2 Strongly agree; 6 agree; 1 neutral; 1 no answer 1 Other options	
Conclusion	Except for one disagreement, the professionals seem to predominantly agree on the positive qualities. There are a few no answers and neutral opinions as well. Thus, a situation that could really be improved. An effective design solution should improve the current situation to more challenging.	

1.11 Question 9

Question No.	9	
Question	From the previous question please write 2-3 qualities you would like to keep at least as good as they are currently.	
Purpose	Understanding ideal situation	
Assumptions	4. That social networking is a viable solution;	
Missing Information	A- What is good about the current situation	
Response	Timely - 3 Empathic - 2	


	<p>Helpful - 2</p> <p>Flexibility</p> <p>Regular</p> <p>It is very important to have close communication with the care circle and to have an update on a timely manner on the progress of the individual who is taken care of.</p> <p>Diverse information and artifact features that are possible to use for free</p> <p>Quick accessibility to information that is not on books or articles</p> <p>Environment friendly tools (less paper usage)</p>	
Conclusion	<p>Green – refer to 8</p> <p>Artefact features were identified as absolute requirements for UX.</p>	


1.12 Question 10

Question No.	10	
Question	Select to show how much you agree with the following qualities of the current communication options regarding the child or adult you care for?	
Purpose	Current situation-evaluation	
Assumptions	<p>1 (a) Time and distance limitations prevent all members of care circle from participating in all meetings;</p> <p>1 (b) Only dedicated professionals can answer queries even when peers/other care circle members might know the answer but need to wait. But, this is a major time and financial investment from professionals;</p> <p>1 (d) Child may be unable to communicate problems between professionals and family members;</p> <p>1 (e) Multiple methods of communication are independently accessed, unstructured and uncoordinated;</p> <p>1 (f) Children are treated as one of many 'patients' or isolated</p>	


	1 (g) It is impossible to provide technical support on AT devices; 4. That social networking is a viable solution;	
Missing Information	B-Definitive list of what is not ideal about the current information	
Response	Reluctant - 3 agree; 2 neutral; 2 no answer; 2 disagree; 1 strongly disagree Ambiguous - 3 agree; 3 neutral; 2 no answer; 1 disagree; 1 strongly disagree Abrupt - 1 agree; 2 neutral; 2 no answer; 4 disagree; 1 strongly disagree Patronising - 2 agree; 1 neutral; 2 no answer; 5 disagree; Other – 3 including apprehensive	
Conclusion	The responses provide some useful points for what to avoid in the UX of the artefact. Even though questions 7 and 8 appear to give a positive view of the current situation, responses from question 10 shows that there are many points for improvement and clearly avoid when designing the solution.	

1.13 Question 11

Question No.	11	
Question	From the above please write the 2-3 most important issues on communication quality that you would like dealt in order of priority because of difficulties now or in the past.	
Purpose	Ideal situation-evaluation	
Assumptions	1 (a) Time and distance limitations prevent all members of care circle from participating in all meetings; 1 (b) Only dedicated professionals can answer queries even when peers/other care circle members might know the answer but need to wait. But, this is a major time and financial investment from professionals;	


	<p>1 (d) Child may be unable to communicate problems between professionals and family members;</p> <p>1 (e) Multiple methods of communication are independently accessed, unstructured and uncoordinated;</p> <p>1 (f) Children are treated as one of many 'patients' or isolated;</p> <p>It is impossible to provide technical support on AT devices;</p> <p>4. That social networking is a viable solution;</p>	
Missing Information	B-Definitive list of what is not ideal about the current information	
Response	<p>Reluctant -3</p> <p>Ambiguous-2</p> <p>Ambiguous – 2</p> <p>Patronising</p> <p>Communication has to be short, precise and clear timely communication is very important;</p> <p>Too much information for one to process in a short period of time;</p> <p>Minimises physical interaction between people.</p>	
Conclusion	The responses prioritise points that need to be considered in the features of the artefact.	

1.14 Question 12


Question No.	12	
Question	Select to indicate how frequently you access the Internet.	
Purpose	Current situation-Demographics	
Assumptions	<p>3. The care circle members own a computer and access the internet;</p> <p>4. That social networking is a viable solution;</p>	
Missing Information	F-Demographics, including IT access, of care circle	
Response	<p>Several times a day – 6</p> <p>Much of the day – 3</p>	

	Few times a day – 1	
Conclusion	Overall this is an encouraging response as all professionals appear to check their emails atleast once a day. However, the scale may have been flawed with 'much' placed below 'several'. This was not picked up in the pilot test. It is not possible to say if the participants looked at where they were visually placed or marked according to what it read.	

1.15 Question 13


Question No.	13	
Question	There may be times when you feel that verbal communication is preferred over written ones that go on record depending on the nature of the matter. How important is it for you to have off the record conversations about the individuals you care for?	
Purpose	Ideal situation	
Assumptions	2. There is a need for frequent communication within care circles 4. That social networking is a viable solution;	
Missing Information	D- What methods of communication are used, and which are preferred, and when	
Response	Not important, everything should be on record -1 Fairly important, an informal chat can be useful – 5 Very important, we need to be as open as possible – 4	
Conclusion	Most professionals believe off the record conversations are useful or very important. Design options should consider text, voice or video chat options where records are not held.	

1.16 Question 14

Question No.	14	
Question	Online social media could potentially offer the following solutions in a single website. Which of the following subjects	

	do you discuss with members of the care circle?	
Purpose	Ideal situation	
Assumptions	4. That social networking is a viable solution;	
Missing Information	E-Opinion on Social networking	
Response	Education - 10 Assessments - 9 Assistive technology - 7 Therapy - 7 Entertainment - 6 Care & Hygiene - 6 Other – 3 Psychological Needs	
Conclusion	The responses clearly list the information in demand in order of priority. This will be taken into account when adding features to the interface.	

1.17 Question 15

Question No.	15	
Question	Online social media could potentially offer the following solutions in a single website. Which of the following functions and features would you like the website to have?	
Purpose	Current situation -Opinion	
Assumptions	4. That social networking is a viable solution;	
Missing Information	E- Opinion on Social networking	
Response	All of the below - 4 Forums or discussions - 8 Feedback on queries about your child-8 Funding assistance - 8 Progress updates for/on your child - 7 Technical support for assistive technologies - 7 Option to choose the information to be shared with each	


	member of care circle - 7 Follow up online assessments - 5 Calendar-5 Extras: File storage and access to helpful information, e.g. downloadable files Other: Information on psychological needs, Support for carers	
Conclusion	More features that the user group would like to use are clearly listed in order of priority. The suggestions clearly show that some of the features requested are mainly used in e-learning environments. This may be a matter of renaming the proposed support site. The last response 'Other' will be an additional section in resources.	

1.18 Question 16

Question No.	16	
Question	If the proposed website was to be a form of social network (such as Facebook, Bebo, LinkedIn, etc.) but specific to support the developmental needs of the child or adult you care for, you may have various opinions and concerns.	
Purpose	Ideal situation – Opinion/negative	
Assumptions	4. That social networking is a viable solution;	
Missing Information	E- Opinion on Social networking	
Response	Privacy and Security 4 Timeliness and reliability of response 3 Time demands for participation and use 2 Time demands and privacy security None	
Conclusion	Except for one, all participants have concerns about social networks. It important that this challenge is met by providing the participants with an assurance that this would be secure,	

	would make their time management more efficient.	
--	--------------------------------------------------	--

1.19 Question 17

Question No.	17	
Question	We are currently investigating the possibility of a social network that hopes to improve the current communication and networking strategies for children. Would you be interested in supporting this investigation by evaluating the interface in development at various stages? It would take approximately three 45 minute sessions over a year.	
Purpose	Future evaluations	
Assumptions	4. That social networking is a viable solution;	
Missing Information	E- Opinion on Social networking	
Response	7 out of 10 participants agreed to participate in future evaluations.	
Conclusion	Most participants have agreed to participate in future studies.	

Questionnaire revisions

The changes made together with the rationale are as follows:

Old Introduction

This survey is conducted to identify the best possible method to address the needs of the family members and professionals involved in the regular decision-makings for a child with special needs. There are seventeen questions and this will take approximately 30 minutes to complete. All data will be used for the purpose of this research only. If you have any queries, you may contact Jennifer George on 079 3080 1010.

Your time and effort is truly appreciated.

New Introduction

Purpose: This survey is conducted to identify the best possible method to address the needs of the family members and professionals involved in the regular decision-makings for a child or adult with special needs.

There are eighteen questions and answering this questionnaire will take approximately 30 minutes to complete. All data will be used for the purpose of this research only. If you have any queries, you may contact Jennifer George on 079 3080 1010 or via email jenni26cg@gmail.com

Your time and effort is truly appreciated.

Definition: The team of people involved in the decision making during a child's development including family members, members of staff at school and medical practitioners are referred to as the *care circle*.

*****BEGINNING OF QUESTIONNAIRE*****

Old Question

(1) Depending on the age of your child, the communication purposes and needs will differ. To help us provide the most appropriate solution, please write the age of your child.

The age of my child is:

PP1 initially thought the questionnaire was not for her as the question referred to 'my child'. Other participants did not have any problems with this question. This phrase has to be rephrased to appear relevant.

New question

(1) Depending on the age of the child or adult you care for, the communication purposes and needs will differ. To help us provide the most appropriate solution, please write the age of the said child or adult.

The age of child or adult I care for is:

(2.3) What is your relationship to the child?

.....

Old Question

(3) Which of the following capabilities of the internet do you use?

(Select all that apply)

- ☐ I do not use the internet
- ☐ E-mail
- ☐ Chat (text or voice)
- ☐ Video messaging
- ☐ Forums or Discussion groups
- ☐ Blogs
- ☐ Social networks
- ☐ Other (specify):

PP4 mentioned that the internet was not 'capable' without its users. It only has features and functions that when used by individuals, supported their capabilities. The question was rephrased to reflect this thought.

New Question

(3) Which of the following features and functions of the internet do you use?

(Mark with *x* all that apply)

- ☐ I do not use the internet
- ☐ E-mail
- ☐ Chat (text or voice)
- ☐ Video messaging
- ☐ Forums or Discussion groups
- ☐ Blogs
- ☐ Social networks
- ☐ Other (specify):

Old Question

(4) You may be using various media to communicate with the schools and support organisations. This could give you the needed flexibility and at the same time complicate things when all those you would like to consult are unavailable or have to duplicate information when using various media.

Please mark in each row below how likely you would be to use the following methods for communication with schools or support organisations for your child?

	Very likely	Likely	Neutral	Unlikely	Very unlikely
Telephone					
Email					
Letter					
Child's homework book					
Periodic meetings or events other					

than annual review					
Annual reviews					
Onsite training					
Social networks					
Online forums and groups					
Other (specify):					

PP3 and PP4 said they disliked the likert matrix. PP3 suggested that a frequency scale would make more sense than a likert. This will also make question 5 redundant, which means one less question. The question and scales were changed to reflect this. PP4 pointed out that annual reviews were not an option. PP3 suggested that order of preference might be beneficial to understand the importance of each of the methods of communication. PP3 mentioned that there should be more space underneath 'Other' to specify and SMS to be added to the list. Although they said they disliked the entire matrix, the specific comments were about the columns only.

New Question

You may be using various media to communicate with the schools and support organisations. This could give you the needed flexibility and at the same time complicate things when all those you would like to consult are unavailable or have to duplicate information when using various media.

(4.1) Please mark with × in each row below how frequently you use the following methods for communication with schools or support organisations for the child or adult you care for?

	Very frequentl y (Weekly)	Frequentl y (1-2 times a month)	Occasionall y (5-10 times a year)	Rarel y (Less than 10 times a year)	Neve r	Order of preferenc e
Telephon e						
SMS						
Email						
Letter						
Child's homework book						
Periodic meetings or events other than annual review						
Onsite training						
Social networks						
Online forums and groups						
Other						

(specify):						
------------	--	--	--	--	--	--

(4.2) Please write in the far right column numbers to show the order of preference for the methods of communication available to you.

Old Question

(5) When you communicate urgently with those involved with your child, you may have a preferred method of communication used in practice.

In case of an immediate need for the child, which method of communication would be your first approach?

(Select only one answer)

- ☐ Telephone
- ☐ Email
- ☐ Write a note on child's homework book
- ☐ Wait for the next event
- ☐ Book onsite training
- ☐ Wait for the annual reviews
- ☐ Discuss it online
- ☐ Search for a solution online
- ☐ Other (specify):

The existing question was replaced based on a response received from PP4 stating that he would search for solutions online in case of emergency. This was turned into a question as the previous question was absorbed into question 4.

New Question

(5) Mark with × to indicate how likely are you to search the internet for a solution for answers to questions you may have about the child or adult you care for?

Very likely	likely	Neutral	unlikely	Very unlikely
-------------	--------	---------	----------	---------------

Old Question

(6) Peer networking with other families or professionals may be beneficial for both practical and emotional support.

How important do you consider communicating with other care circles?

Please circle on box below:

Very important 5	Important 4	Neutral 3	Not important 2	Not important at all 1
------------------------	----------------	--------------	--------------------	------------------------------

PP4 recommended that the term 'care circle' is defined. PP3 suggested that 'No opinion' made more sense than 'neutral'. Both suggestions were taken into account when revising the question. Circling the box was changes ""to mark with ×' to be consistent with other question and the numbers removed.

New Question

(6) Peer networking with other families or professionals may be beneficial for both practical and emotional support members of the care circle¹.

Mark with × to show how important you consider communicating with other *care circles*?

Very important	Important	No opinion	Not important	Not important at all
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¹ The team of people involved in the decision making during a child's development including family members, members of staff at school and medical practitioners are referred to as the *care circle*.

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Old Question

(7) With the variety of communication modes at your disposal, you may find they are either used to it highest potential or inefficiently.

How would you grade the current modes of communication with professionals and family members involved in the care of your child?

Very good	Good	Average	Poor	Very Poor
1	2	3	4	5

PP3 mentioned that the word 'mode' sounded too technical. This was changed to 'ways to communicate'. The word 'grade' was changed to 'judge'. The word 'okay' was preferred over 'average' by PP3. The numbers were also removed.

New Question

(7) With the variety of ways to communicate at your disposal, you may find they are either used to it highest potential or inefficiently.

Mark with × to show how you would judge the current ways of communication with professionals and family members involved with the child or adult you care for?

Very good	Good	okay	Poor	Very Poor
-----------	------	------	------	-----------

Old Questions

(8) In assessing the current situation with communication options, there may be varied opinions on the various factors that make communication effective.

How would you rate the following qualities regarding the current communication options regarding your child?

(Select all that apply)

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Timely					
Reluctant					
Helpful					
Flexible of alternatives					
Regular					
Empathetic					
Ambiguous					
Abrupt					
Patronising					
Other (specify):					

(9) From the above please list the 2-3 qualities you would like to keep at least as good as they are currently

1.
2.
3.

(10) From the above please list the 2-3 most important issues on communication quality that you would like dealt in order of priority:

1.
2.
3.

Questions (8) – (10) are all linked and were the most problematic and confusing for all four participants. PP2 got the answers quite obviously wrong by misinterpreting the question to qualities of the child and PP1 decided to write explanations for her answers in the boxes. PP3 said 10 out of 20 minutes were spent on this question and PP4 found the question too complicated. PP3 explained that the confusion was mainly due to positive and

negative opinions being mixed in the matrix. Also that if they were split accordingly, questions (9) and (10) could also be moved to be after the positive and negative questions. This was taken on board and changes were made.

New Questions

(8) *In assessing the current situation with communication options, there may be varied opinions on the various factors that make communication effective.*

Mark with × to show how much you agree with the following qualities of the current communication options regarding the child or adult you care for?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Timely					
Helpful					
Flexibility of alternatives					
Regular					
Empathetic					
Other (specify):					

(9) From the above please write 2-3 qualities you would like to keep at least as good as they are currently.

1.
2.
3.

(10) Mark with × to show how much you agree with the following qualities of the current communication options regarding the child or adult you care for?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

Reluctant					
Ambiguous					
Abrupt					
Patronising					
Other (specify):					

(11) From the above please write the 2-3 most important issues on communication quality that you would like dealt in order of priority because of difficulties now or in the past.

1.
2.
3.

Old Question

(11) *There may be family members who wish to participate in the discussions and decision-making regarding a child, but are unable to do so for various reasons.*

Is there any special need of the family member that makes it challenging in participating in the decision making of a child's progress?

(Select all that apply)

- ☐ Language limitations of family members
- ☐ Motor or Physical disabilities of family members
- ☐ Learning or Cognitive disabilities of family members
- ☐ Computer competency challenges of family members
- ☐ Do not have internet connection at home and/or work
- ☐ Other (specify):

This question appeared redundant to PP2 as there were no special requirements. The option 'no' was added as the first answer. PP3 mentioned a line or a box would be more encouraging to write answers for the 'Other (specify)' option.

New Question

(12) *There may be family members who wish to participate in the discussions and decision-making regarding a child, but are unable to do so for various reasons.*

Mark with × to all relevant answers to indicate if there is any special need of a family member that makes it challenging in participating in the decision making of a child's progress?

- ☐ No
- ☐ Language limitations of family members
- ☐ Motor or Physical disabilities of family members
- ☐ Learning or Cognitive disabilities of family members
- ☐ Computer competency challenges of family members
- ☐ Do not have internet connection at home and/or work
- ☐ Other (specify): _____

Old Question

(12) How frequently do you access the Internet?

Much of the day	Several times a day	Few times a day	Once a day	Every few days	Once a week	Few times a month	Once a month	Several times a year	Almost never
1	2	3	4	5	6	7	8	9	10

Numbers were removed and the question was rephrased with instructions on answering.

New Question

(13) Mark with a × to indicate how frequently you access the Internet.

Much of the day	Several times a day	Few times a day	Once a day	Every few days	Once a week	Few times a month	Once a month	Several times a year	Almost never
-----------------------	---------------------------	-----------------------	---------------	----------------------	-------------------	----------------------------	--------------------	----------------------------	-----------------

						month			
--	--	--	--	--	--	-------	--	--	--

Old Question

(13) There may be times when you feel that verbal communication is preferred over written ones that go on record depending on the nature of the matter.

How important is it for you to have off the record conversations about your child?

(Select one answer)

- ☐ Very, it is important to be honest
- ☐ Can be useful, good to have them
- ☐ No, everything should be on record
- ☐ Other (specify):

PP1 and PP2 answered the question without any problems but PP4 pointed out that the answers did not answer the question and mentioned the answer referring to honesty implied dishonesty, which would be offensive. All answers were revised.

New Question

(14) *There may be times when you feel that verbal communication is preferred over written ones that go on record depending on the nature of the matter.*

How important is it for you to have off the record conversations about the child or adult you care for?

(Select one answer by marking with a x)

- ☐ Very important, we need to be as open as possible
- ☐ Fairly important, an informal chat can be useful
- ☐ Not important, everything should be on record

Old Question

(14) Online social media could potentially offer the following solutions in a single website.

Which of the following subjects do you discuss with members of the care circle?

(Select all that apply)

- ☐ Education
- ☐ Entertainment
- ☐ Assistive technology
- ☐ Therapy
- ☐ Assessments
- ☐ Care & Hygiene
- ☐ Other (specify):

This question was answered comfortably by all participants. Numbers were removed and the question was rephrased with instructions on answering.

New Question

(15) Online social media could potentially offer the following solutions in a single website.

Which of the following subjects do you discuss with members of the care circle?

(Mark with a x all that apply)

- ☐ Education
- ☐ Entertainment
- ☐ Assistive technology
- ☐ Therapy
- ☐ Assessments
- ☐ Care & Hygiene
- ☐ Other (specify):

Old Question

(15) Online social media could potentially offer the following solutions in a single website.

Which of the following capabilities would you like the website to have?

(Select all that apply)

- ☐ Progress updates for/on your child
- ☐ Feedback on queries about your child
- ☐ Follow up online assessments

- ☐ Funding assistance
- ☐ Technical support for assistive technologies
- ☐ Should be able to view previous records
- ☐ Option to choose the information to be shared with each member of care circle
- ☐ Calendar
- ☐ Audio/Video chats
- ☐ Forums or discussions
- ☐ Being able to print copies of discussions
- ☐ All of the above
- ☐ None
- ☐ Other (specify):

This question was answered comfortably by all participants but was revised according to the general suggestions, numbers were removed and the question was rephrased with instructions on answering. The word 'capabilities' was changed according to suggestion for question (3). 'All of the above' was changed to 'All of the below' to save time for participants if they would like all possible options.

New Question

(16) Online social media could potentially offer the following solutions in a single website.

Which of the following functions and features would you like the website to have?

(Mark with a × all that apply)

- ☐ All of the below
- ☐ Progress updates for/on your child
- ☐ Feedback on queries about your child
- ☐ Follow up online assessments
- ☐ Funding assistance
- ☐ Technical support for assistive technologies
- ☐ Should be able to view previous records
- ☐ Option to choose the information to be shared with each member of care circle
- ☐ Calendar
- ☐ Audio/Video chats
- ☐ Forums or discussions
- ☐ Being able to print copies of discussions
- ☐ None
- ☐ Other (specify): _____

Old Question

(16) If the proposed website was to be a form of social network (such as Facebook, Bebo, LinkedIn, etc.) but specific to support your child's development, you may have various opinions and concerns.

What concerns would you have if an online network was launched to address the needs of communication?

(Select all that apply)

- ☐ None
- ☐ Privacy and Security
- ☐ Timeliness and reliability of response
- ☐ Time demands for participation and use
- ☐ Other (specify):

Numbers were removed and the question was rephrased with instructions on answering.

New Question

(17) If the proposed website was to be a form of social network (such as Facebook, Bebo, LinkedIn, etc.) but specific to support your child's development, you may have various opinions and concerns.

What concerns would you have if an online network was launched to address the needs of communication?

(Mark all that apply with a ×)

- ☐ None
- ☐ Privacy and Security
- ☐ Timeliness and reliability of response
- ☐ Time demands for participation and use
- ☐ Other (specify):

Old Question

(17) and (18) We are currently investigating the possibility of a social network that hopes to improve the current communication and networking strategies for children.

Would you be interested in supporting this investigation by evaluating the interface in development at various stages? It would take approximately three 45 minute sessions over a year.

(Select only one answer)

- ☐ Yes*
- ☐ No

(18) *If yes, please provide your contact details:

Name:

Email or Postal address:

.....

.....

.....

.....

All four participants answered these two questions comfortably. The instructions for answers were rewritten and both questions were merged by removing the number.

New Question

(18) *We are currently investigating the possibility of a social network that hopes to improve the current communication and networking strategies for children.*

Would you be interested in supporting this investigation by evaluating the interface in development at various stages? It would take approximately three 45 minute sessions over a year.

(Mark with a × only one answer)

- ☐ Yes*
- ☐ No

*If yes, please provide your contact details:

Name:

Email or Postal address:

.....

.....

.....

.....

*****END OF QUESTIONNAIRE*****

Worthwhile Outcomes	Enhance Capabilitie	Efficient Communication	Enhanced Education	Happier Homes	
Worthwhile Experience	Helpful and Rewarding	Motivating	Enjoyable and Fun	Satisfying	
Qualities	Efficient, accurate and Informative	Thorough, considerate and complete	Confidence and Satisfaction		
Features	Can have more frequent meetings	Cut down travel cost and time	Entire care circle can be involved in decisions		
Materials					
Adverse Experience	Need to wait six months for review	Assessment and travel time and cost	Entire Care Circle cannot be present	Existing Care Circle is unstructured	Decisions are biased
Adverse Outcomes	Lack of timely response	Waste of time	Solution does not consider entire Care Circle		

Design Document

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1. Site Goals

1.1. *Short-term goals*

- To share progress of motor impaired
- Conduct Assessments of the motor impaired remotely
- Provide therapy and therapy related information remotely
- Choice and support in using assistive technology

1.2. *Long-term goals*

- Enabling suitable education by providing information on suitable schools and other learning opportunities for children
- Supporting and training both professional and family carers to care for motor impaired
- Provide entertainment and related information
- Provide information and guidance on care & hygiene
- Support psychological needs of motor impaired and members of care circle
- Provide details of funding opportunities

2. User Experience

2.1. *Target Audience*

- Primary – Family members, professionals
- Secondary – extended family members, support workers

2.2. *Why would people come to the site?*

- Participate in assessment of a motor impaired
- To make decisions as a team
- See progress of a motor impaired they care for
- For peer support
- Seeking information on education, assistive technology, care & hygiene, funding
- To find suitable entertainment for motor impaired

2.3. *Scenarios*

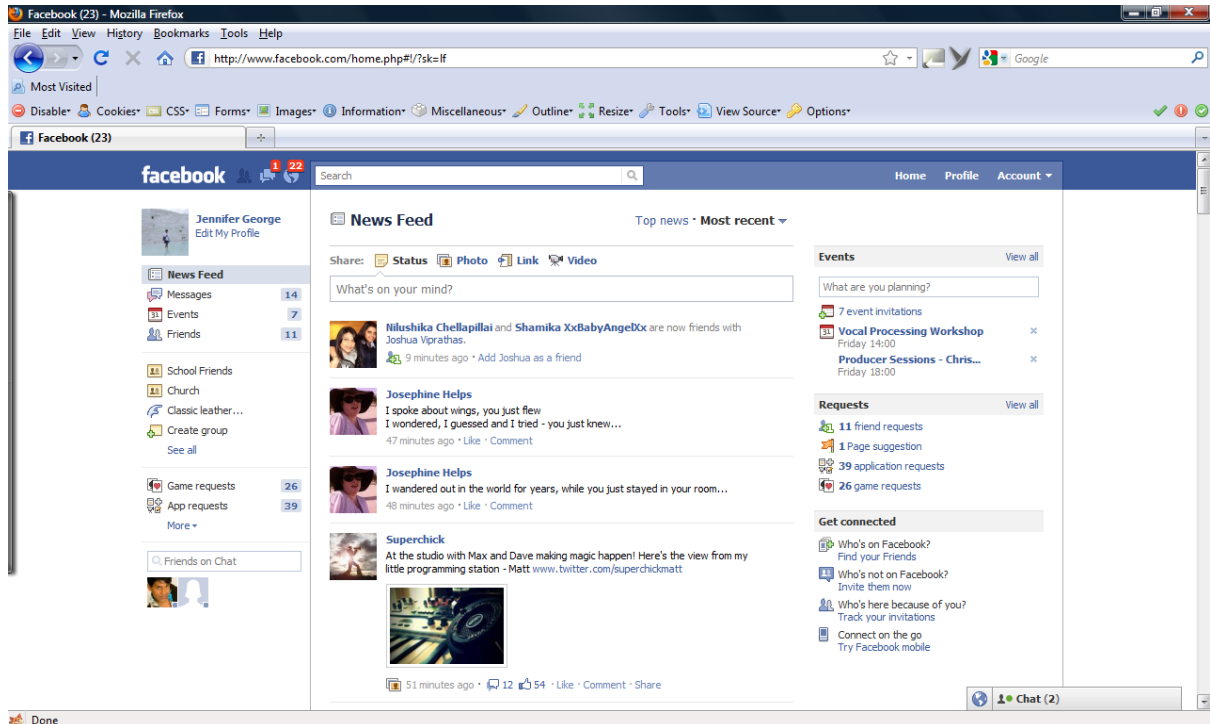
Scenarios: an informal narrative story, simple, 'natural', personal, not generalisable

- When a child is first diagnosed with a motor impairment such as Cerebral Palsy, the social worker recommends that the mother joins the website. The mother looks up the information section and finds documents with information and support on 'Cerebral Palsy'.
- Mother invites the social worker, special educational needs teacher and speech and language therapist to join the child's network on the website.
- The entire team builds the social space with information about education, communication, feeding, financial support, fundraising, therapy, etc.

- Mother videos the child communicating and eating and shares the video with the speech and language therapist and the teacher. The therapist proposes a few assistive devices; the family members and other care circle members consider it and choose collaboratively.
- Mother regularly posts a progress update using photos, videos and notes to inform those involved in education and medical support of the progress so that they could make further suggestions.
- Mother will invite other parents from the school of the child to join the care circle.
- When the therapists are unreachable, the mother posts any concerns or questions on the website in the form of text, photos or videos. Other parents can respond from experience or when the therapist does become available, they can see the entire content and respond after checking any records which are also available on the website;
- The care circle can also gradually build a document or profile on how the child communicates which will become useful for any new teacher or therapist when they take over. This will also reduce duplication of information and makes training easy;
- Having connected with a number of people on the care circle, if the mother has any security concerns, she will visit the information on security;
- Mother will be alerted via mail with regular news of relevant information upon request; She could also choose to share any interesting information she finds with others, and if others share same, she can set up to receive alerts;

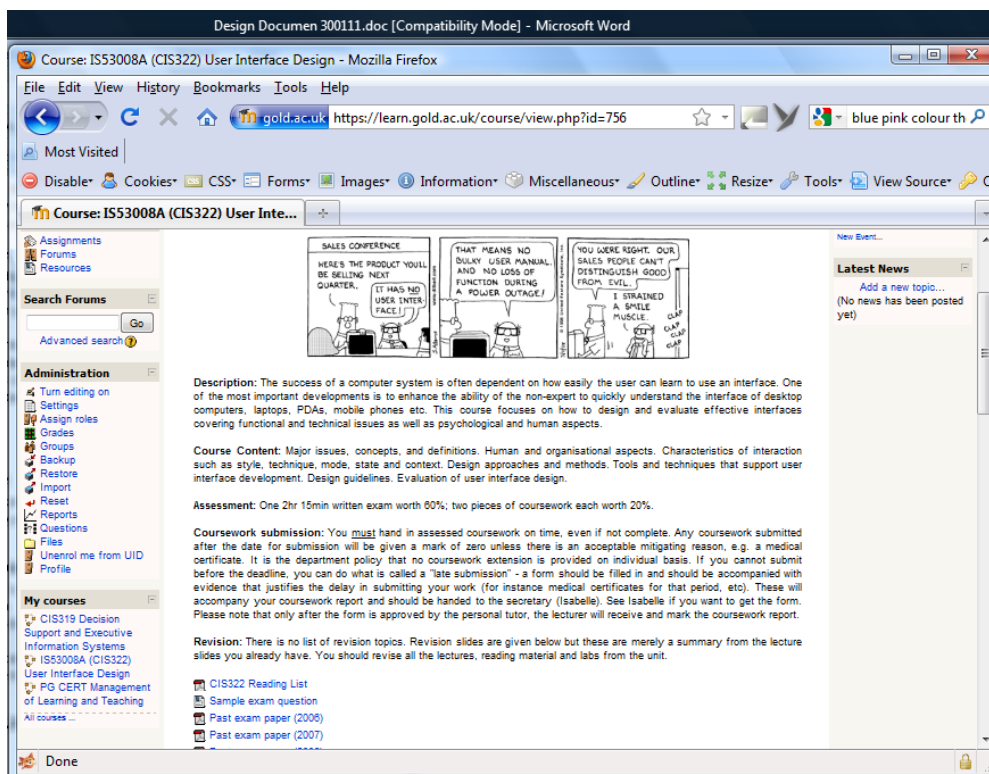
2.4. Competitor Analysis

2.4.1. Facebook



- Member logon pages: invitations can be provided and accepted via email. However, this gives little control over identifying specific care circles.
- Option to choose the information to be shared with each member of care circle: It is possible to create groups and share information with them. Once you have a group, it is not possible to restrict some and not others;
- Video/Audio/text Chat: Only text based one to one chat
- Forums or discussions - Can share photos, videos and text: yes with each 'profile'
- Calendar: Not available but can organise events and receive reminders
- Signup pages for email newsletters/updates: 'Like's to organisations will permit receiving new updates;
- File storage and access to helpful information, e.g. downloadable files: only links and audio or video files can be shared. Common formats of files such as pdf, .doc are not compatible;
- Interface design: cannot be manipulated;

2.4.2. Moodle



- Member logon pages: can add or allocate privileges to each member. It is possible to create groups and manage privileges.
- Option to choose the information to be shared with each member of care circle: group 'leader' can decide on privileges.
- Video/Audio/text Chat: there could be plug-ins for a/v
- Forums or discussions: Can share photos, videos and text
- Calendar: Yes
- Signup pages for email newsletters/updates: notifications could be set up for activities.
- File storage and access to helpful information, e.g. downloadable files: Yes
- Interface Design: can be manipulated within the set structure. CSS could be controlled to suit the website;

3. Site Content

3.1. *Content Elements*

- Progress updates for/on your child
- Technical support for assistive technologies
- Follow up online assessments
- Funding assistance
- Psychological needs
- Support for carers
- Shared photos, videos, text
- Copyright notices
- Privacy statement
- Membership rules

3.2. *Functional Elements*

- Member logon pages
- Option to choose the information to be shared with each member of care circle
- Video/Audio/text Chat
- Forums or discussions: Can share photos, videos and text
- Calendar
- Signup pages for email newsletters/updates
- File storage and access to helpful information, e.g. downloadable files

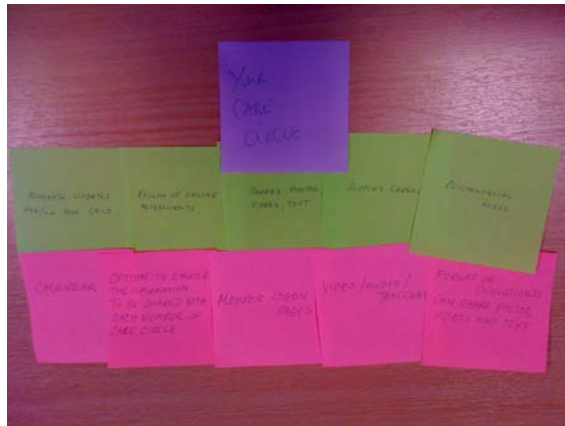
3.3. *Group and label content (Card Sort)*

Pink - Features

Green Content

Purple - Category

Card Sort 1



4. Site Structure

4.1. *Metaphors*

Participant	Colour of care	Shape of care	First Visuals	Other ideas
Chris Helps	pale blue	pillow shaped	U like a comfortable hammock	
Ian	pink	circle	mother	
Michael	blue	round	red cross	
Jo	light blue	medical cross	hands, arms, holding/enveloping	
Itai	blue	round	helping	hands and hearts
Matt	blue	heart	Old peoples' homes, mental help facilities	hugs and holding hands
Rodney	pink (fusion) & cyan	circle	hands	"to love is to care"
Djonny	Red	heart	vulnerable people	Smile, hugs, tears
Winnie	sky blue	round	holding hands, young and old hugging and smiling/sdult and child holding hands and walking	cats or dogs licking people or their peeps' wound
Vicky	light green	circle	cuddle	cuddle; love, support, respect, smile cry
Chris Hambly	pink	circle	hand; faces	hand; faces
Gillian	warm blue moving towards pink	round/elliptical	hug	hand stroking, smile, sun break through cloud
Joy	pink	heart	big hand holiding small hand	big hand holiding small hand
Dilhara	blue or yellow	circle	big hand reaching out to small hand	Heart





Family: stereotypical family? Both parents, 1 son and 1

daughter + baby

Collaborative work: across table

Education: books, computers

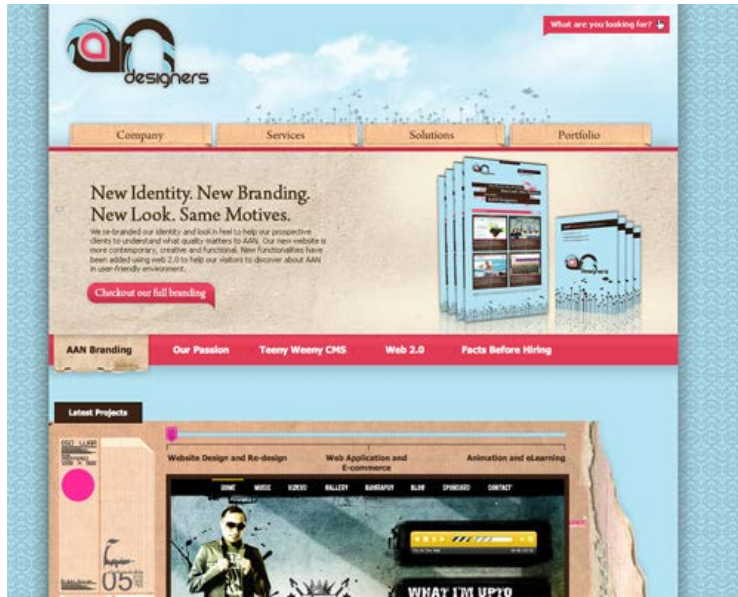
Medics: stethoscope, white medic gown, mask



4.2. *Hierarchical Structure*

4.3. *Navigation Definition*

5. Colour Themes Ideas



<http://www.smashingmagazine.com/2010/01/28/color-theory-for-designers-part-1-the-meaning-of-color/>



<http://www.itakeyou.co.uk/wedding-ideas/wedding-theme/gold-pink-turquoise-colour-pallet.htm>



<http://www.itakeyou.co.uk/wedding-ideas/wedding-theme/pink-pistachio-blue-colour-pallet.htm>

References

http://www.webmonkey.com/2010/02/Information_Architecture_Tutorial/

Requirement Specification

Aim

We want professionals and family members who care for individuals with motor impairment to form care circles, network with other professionals and parents, discuss and debate issues and thereby improve the capability of the individual with the impairment. By nature this will be a cross between a social network and an e-learning environment but will need to be appropriately named.

Commented [J1]: There is also the need for a information repository which is not usually part of a social network; the interaction experience should be similar to a social network;

The purpose of the design solution is to enable the information obtained with regard to the motor impaired:

- Timely
- Helpful
- Flexibility of alternatives
- Regular
- Empathetic
- Diversity of materials that is possible to use for free
- Quick access to information that is not on books or articles
- Environment friendly tools (less paper usage)

Commented [J2]: Question 8, 9

We also seek to reduce:

- Reluctance
- Ambiguity
- Abruptness (may be have further explanation with a 'see more...')
- Patronising content
- Making the user feel apprehensive

Commented [J3]: Question 10, 11

1. Registration

The legal guardian of the individual concerned should add member, select relationship and send an invite to those they think is involved in the support and care of the child or adult they care for (Care Circle member). The care circle member should click on the link, accept and register.

The user (the added individual) should be able to confirm or change their relationship to the individual with motor impairment concerned. E.g. if the guardian added him or her as teacher when in fact a teaching assistant, this change should be possible and if this does not exist, the user should be able to define their own. In addition the user should also be able to select an 'Other' option and define their role if it doesn't exist in the list. The following options could be given in a drop down.

Professionals

Speech and Language Therapist

Speech Pathologist
Teacher
Special Education Teacher
Occupational Therapist
Physician coordinates
GP (General Physician)
Paediatrician
Psychomotrician
Social Worker
Health visitor
Nurse-Practise/District/Hospital
Carer
Health Care Assistant
Physical Therapist
Psychologist
Child and Adolescent Mental Health Services
Primary Care Trust
Autistic Advisory Service
Educational Interventionist
Physical Education Teacher
Neurologist
Orthopaedist
Nutritionist
Technologist

Family member

Mother
Father
Brother
Sister
Parents
Grandmother
Grandfather
Grandparents
Aunt
Uncle
Relative
Family friend
Step mother
Step father
Step brother
Step sister
Step grandfather
Step grandmother

Once registered, the member should be able to see the 'profiles' of other care circle members.

Commented [J4]: Questions 2.2 and 2.3

Commented [J5]: Should know the care circle at a glance;
Question 6

Login afterwards should be by typing email and password.

Commented [J6]: Similar to most social networks

2. Primary Features

The legal carer should have control over what features should be viewed or used by each care circle member.

Commented [J7]: Question 17

The following features should be available for the care circle member's usage.

- Forums or discussions
- Feedback on queries about your child
- Progress updates for/on your child
- Text, voice or video chat options where records are not held
- Follow up online assessments
- Calendar
- File storage and access to helpful information, e.g. downloadable files
- Should be able to view previous records

Commented [J8]: Question 15

It is important to be able to select entire care circle or select or deselect specific members of the care circle to share content. You should also be able to add further members during the discussion later on.

Commented [J9]: Question 14

For members of the care circle who would only use off line methods such as homework books or printouts of communication (i.e. printed copies) an authorised care circle member should be able to add them as 'offline' participants and print off. This authorisation should be done only by the official carer as this could involve protected personal information i.e. postal address.

Commented [J10]: Question 4

Commented [J11]: Question 17

3. Content Categories

This section will be for all care circles.

There will be some default content on the following sections. However, the contents on the following categories will be added and shared by care circle members.

Assessments
Assistive technology
Care & Hygiene
Education
Entertainment
Funding assistance
Psychological Needs
Support for carers

Therapy

Technical support for assistive technologies

Commented [J12]: Question 14, 15

There should be a 'share' option for any discussion of post which could send a URL via email.

Commented [J13]: Participant triangulation of Question 5

.....
Details to follow:

4. Usability

Good usability and accessibility could potentially reduce many of the challenges faced by the care circle members and if the social network is successful, other translations could also be considered.

Commented [J14]: Question 12

5. User Experience (UX)

UX – a graphical representation of the size of each care circle would be useful. This could be used to motivate the care circle members to get more members of the care circle involved.

Consider:

Privacy and Security

Timeliness and reliability of response

Time demands for participation and use

Commented [J15]: Questions 17

6. Accessibility

The site must comply with W3C WAI (World Wide Web Consortium Web Accessibility Initiative) level AA Guidelines.

Commented [J16]: Question 12

7. Code validation

All code on the site should validate to W3C (World Wide Web Consortium) specifications.

8. Search Engine Optimisation

This can be ignored for this beta version.

9. Maintenance

The site will need regular changes until August 2011 based on systematic user evaluation. Any changes further to November 2011 (following the undergraduate degree submission of the web developer) will be reviewed.

10. Hosting

A reliable web host will be found for the completed site and access given to the designer who will load the site onto the web and set up E-mail, FTP access, and carry out any other administration necessary to set up the site.

11. Support

Any bugs or errors found on the site after launch will be rectified.

Could we monitor log-in and usage?

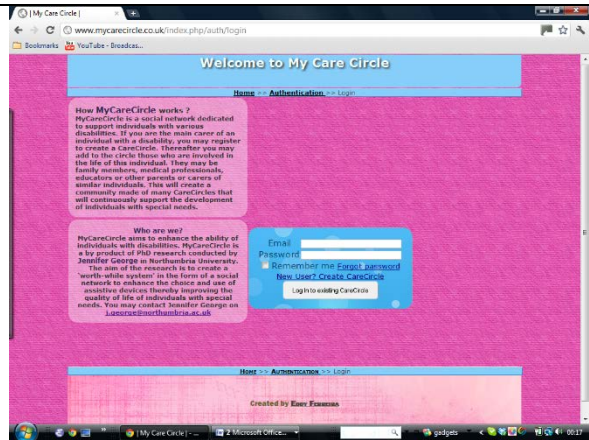
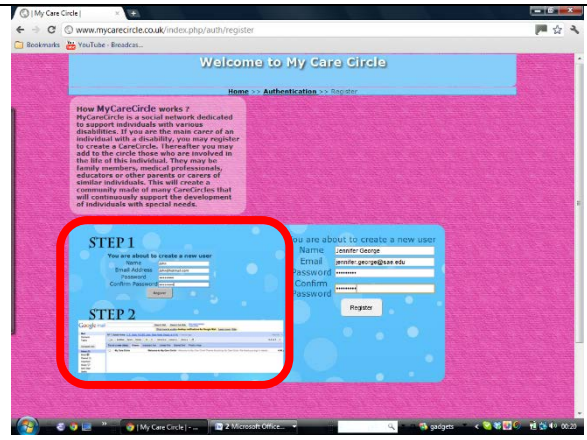
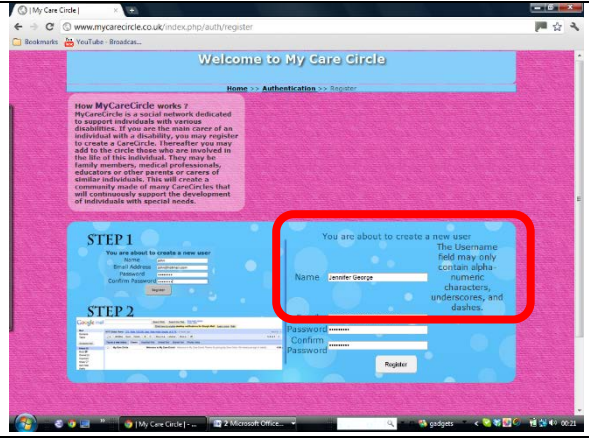
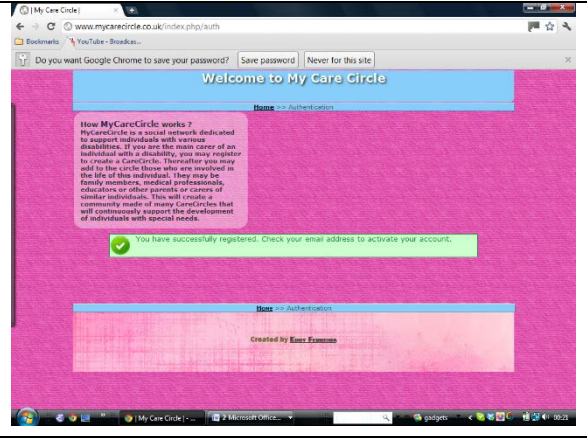
References

C8 – Cognitive Walkthrough

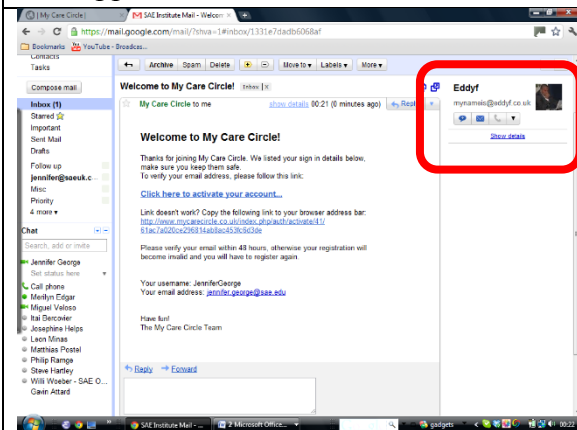
The reading order is from left to right of the table and the numbers in brackets refer to the response to the four cognitive walkthrough questions asked at each step.

8.1.1.1. Registration, Invitations and Log-in

Table 8.1 – Registration, Invitations and Log-in

1. Register on MCC using full name and email	
	
<p>(1)-(4) The option to Login or Register is clear.</p>	<p>(1), (2), (4) For registration, the details on the right are clear. (3) The instructions with screenshot on the left of the screen are quite confusing for Rachel as there is no description for the text. Both Susan and John ignore the instructions on the left and continue with the task as they would in any other registration process.</p>
	
<p>(1) - (4) 'Name' does not indicate that it should be 'Username'. For security reasons, it should ask user to type surname and forename.</p>	<p>(1)-(4) Clear instruction to check email for confirmation, successful step.</p>

A visual to indicate which section(s) have been completed incorrectly would be useful. This applies to all three Personas.



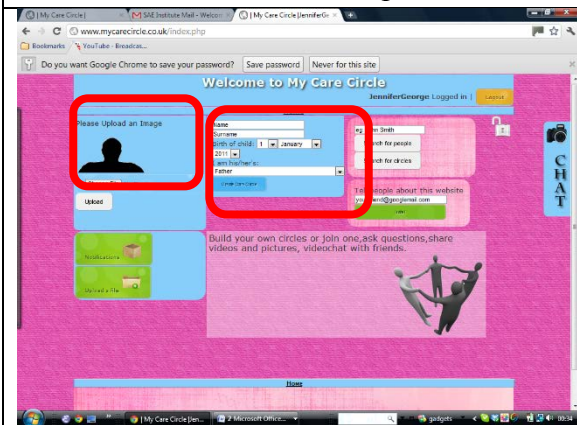
(1), (4) Email confirmation received: Content of the message is standard and clear to all three personas. (2) They are however left wondering who 'EddyF' is as they do not know the programmer. The message should either be sent from the researcher's email or a dedicated My MCC email. (3) N/A



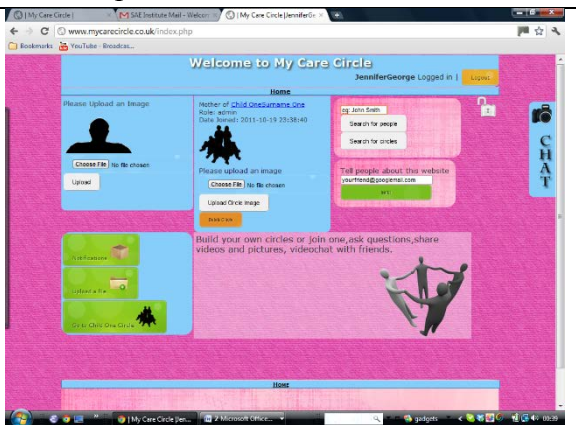
(1)-(4) Log-in following registration is straightforward and clear to all three personas.

2. Create Care circle:

- Complete profile
- Select relationship to the cared for from drop down



All three personas encountered issues on this page and were unable to proceed. (1)-(3) An instruction to create a care circle should be above the form to be completed. It is also unclear whose name and surname should be inserted. Upon click, the text in field should disappear. It

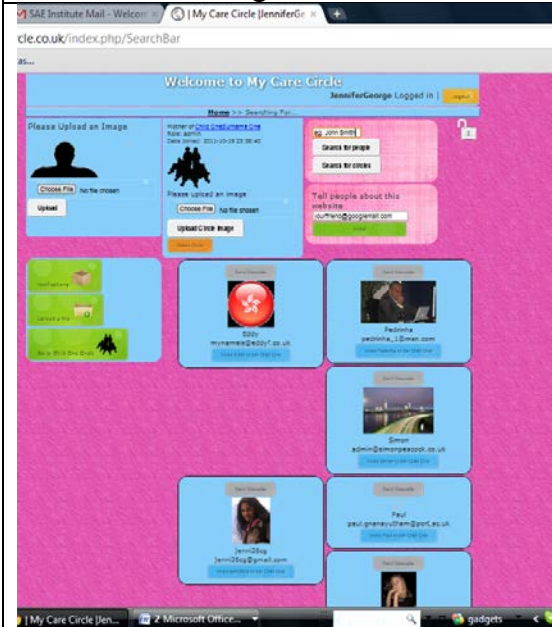


(1)-(3) Uploading picture is more confusing as this appears in two places for all three personas. With the first line reading as Mother of ..., it leads the user to upload their own picture. This could be simplified by saying 'Upload your picture' and 'Upload child's photo'. Image uploads work fine.

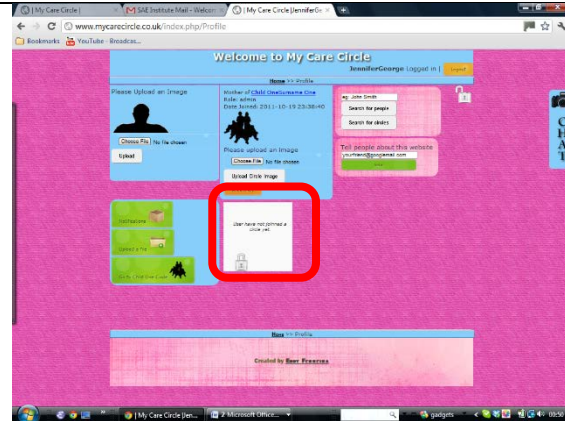
(4) Yes.

is also unclear whose picture should be uploaded.
(4) Yes.

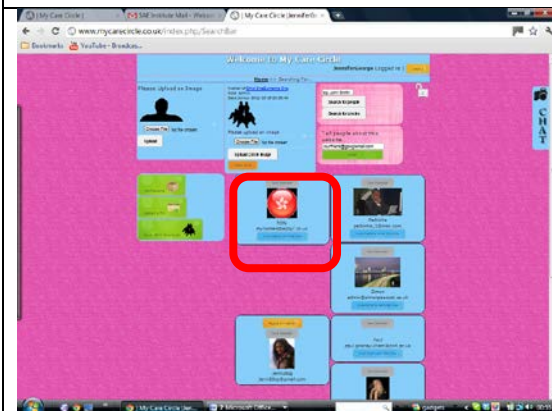
3. Invite new members to MCC a. Existing users



(1)-(4) 'Search for Circles' and 'Search for People' options are both obvious to all three personas. The results are displayed clearly. 'Send Invite' link is clear.



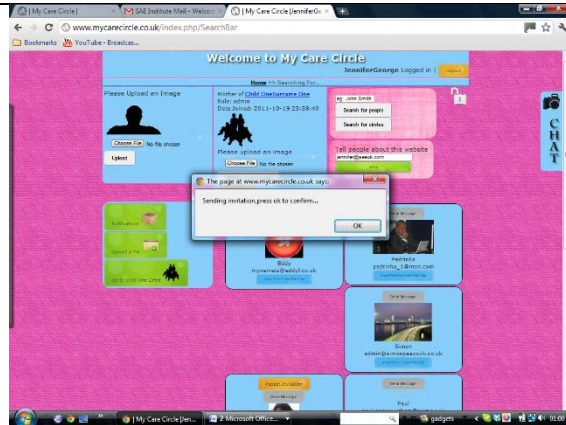
(1)-(4) When 'Invite' link is clicked the above message appears. The message is clear, but the lock icon is confusing to all three personas. Susan and John ignore the message but Rachel is confused and wonders what the lock icon might mean.



(1)-(4) If people who have already received an invitation are searched for again, a message appears above the result saying 'Reject Invitation'. All three personas find this confusing. This should read as 'Invitation sent. Uninvite'

3. Invite new members to MCC

b. New users

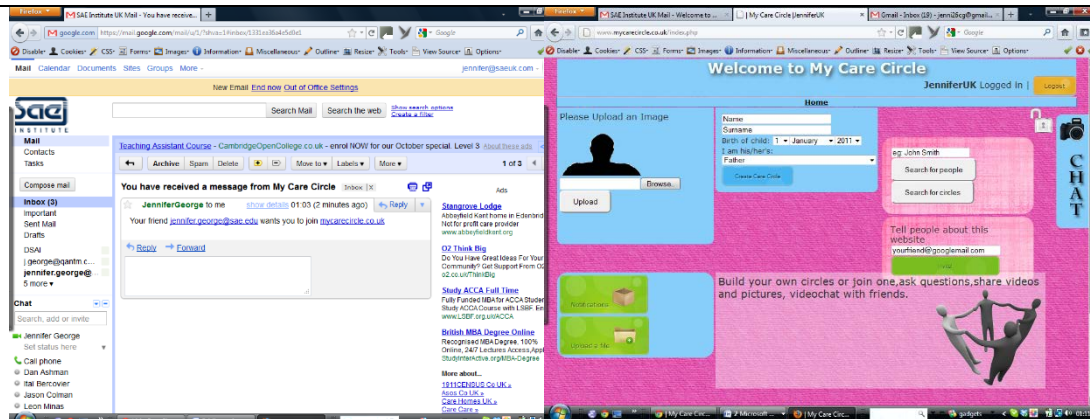


(1)-(4) Quite straightforward for all three personas to enter email and then select confirmation.

4. Care circle member:

a. Accept invitation

b. Register

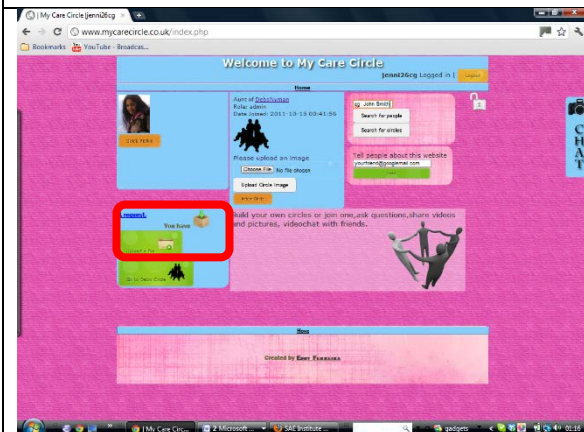


(1)-(4) All three personas check email and note that invitations have been received. However, the inviter's name does not appear and they are not aware who invited them. This should appear in the message.

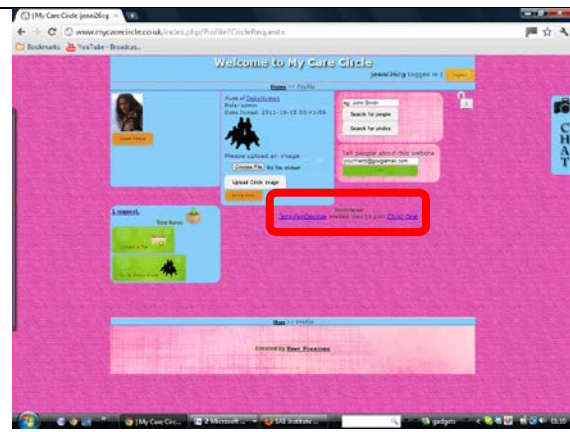
(1)-(4) All three personas accepted invitation to join website and signed up. However, it misled all of them to believe it was an invite to join the care circle of the inviter as opposed to registering on the website.

It was also unclear to the inviter if any of the three personas had joined the MCC as there was no associated notification. It seems that the inviter needs to keep searching and checking if this member has registered and then invite to join a particular care circle again. The word 'Join' is also confusing.

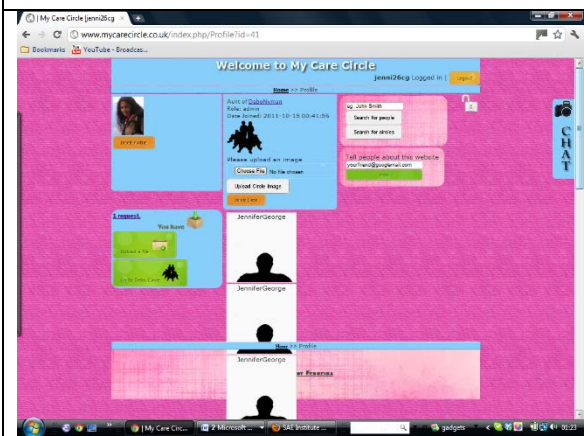
4. Care circle member:
c. Join care circle



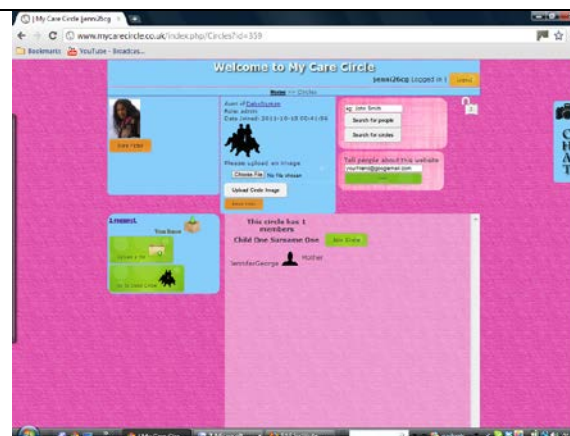
(1)-(4) All three personas are able to see any invitations to join care circles under notifications sections. However, there was no email to indicate that someone has invited them and this is a surprise. The “notifications is full” statement also adds to the confusion.



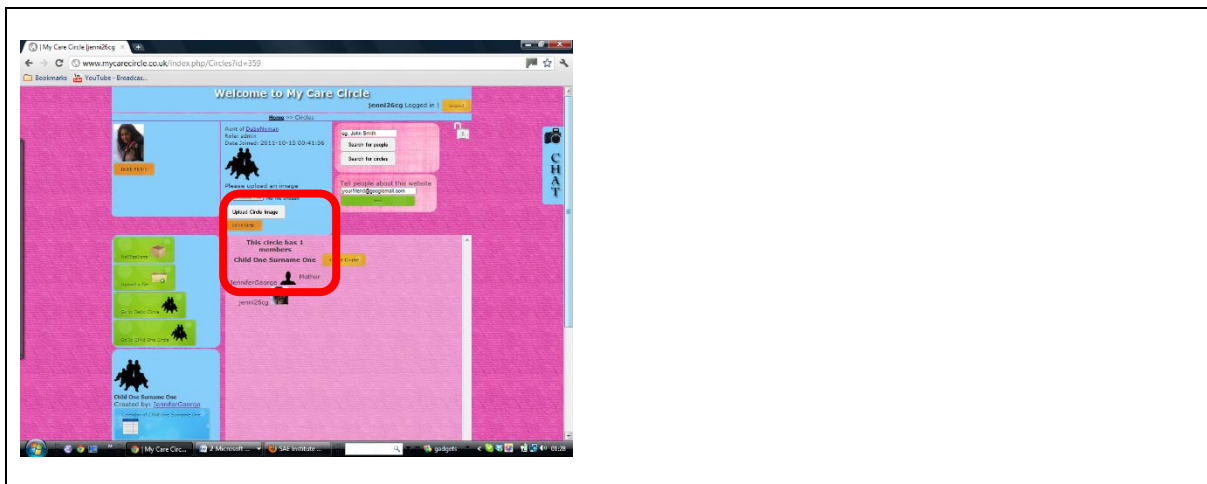
(1)-(4) If ‘1 request’ is clicked, the above notice appears. The next step is unclear. If care circle’s name is clicked, it takes the personas to the following page.



(1)-(4) When the name of invitee is clicked, the profile gets listed repeatedly, which is a dead end for all three personas (bug).



(1)-(4) When the name of the care circle was clicked, it guided all three personas to the Join Care Circle page which had details of the care circle – success.



(1)-(4) Once joining, it lists all memberships. The extra step to Join twice can be avoided which will also eliminate the confusion. The care circle however lists incorrect number of members in the care circle. (bug)

5. The 'new' member should be able to see the 'profiles' of other care circle members

This feature has not been implemented.

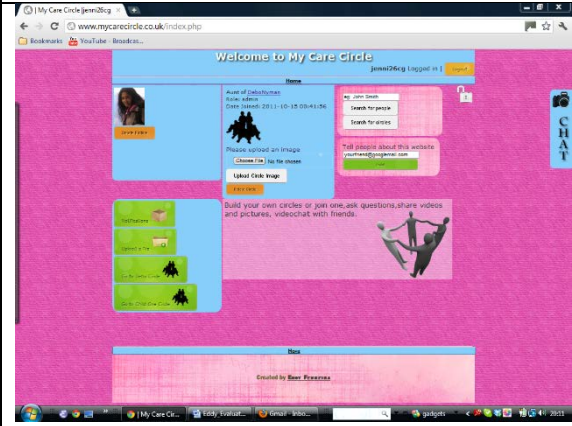
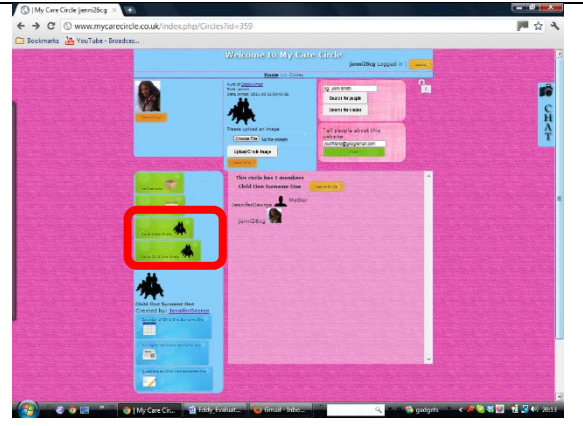
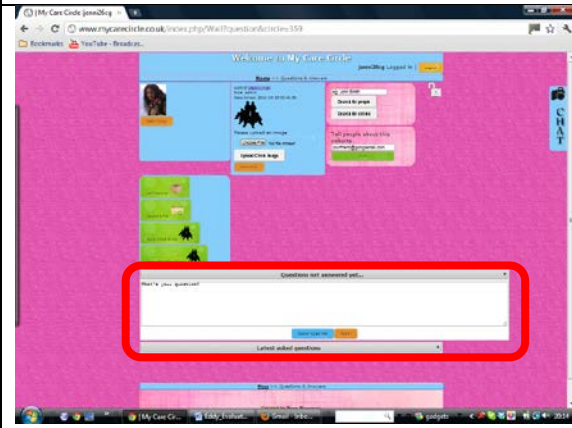
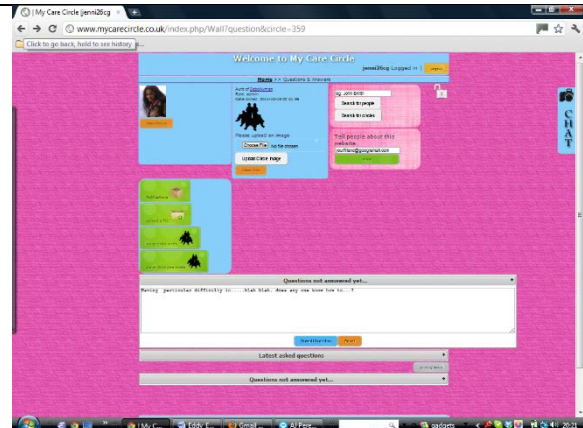
6. The care circle creator should be notified and he or she should accept the registration.

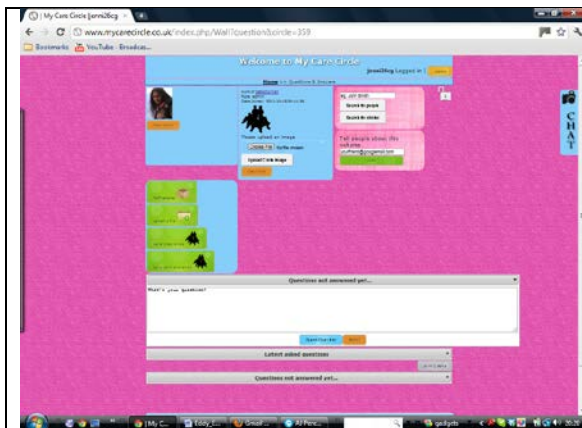
This feature has not been implemented.

8.1.1.2. Usage

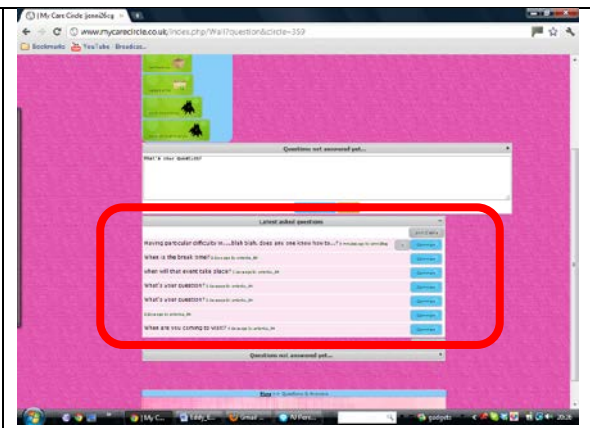
Table 8.2 – Usage

1. Start discussions on forums
2. Contribute to discussions on forums
3. Receive feedback on queries about child concerned

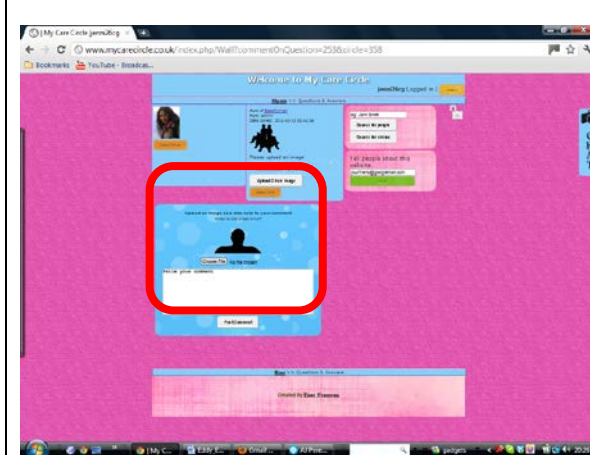
	
<p>(1)-(4) For all three personas it is unclear how to get to the Forum and therefore cannot get past seeing the option 'discussions'.</p>	<p>(1)-(4) Once the care circle has been clicked, the 'Questions on...' appears underneath. All three personas understand this. However, 'Ask Questions' might be more direct than 'Questions on..'</p>
	
<p>(1)-(4) Posting a question has clear visual instructions. All three personas are pleased with this – success.</p>	<p>(1)-(4) However, the default text should ideally disappear as soon as a user clicks in the field. Once the persona submitted a question, an additional option appears to have appeared underneath the text box. These options are unclear until they are read a few times and should be simplified.</p>



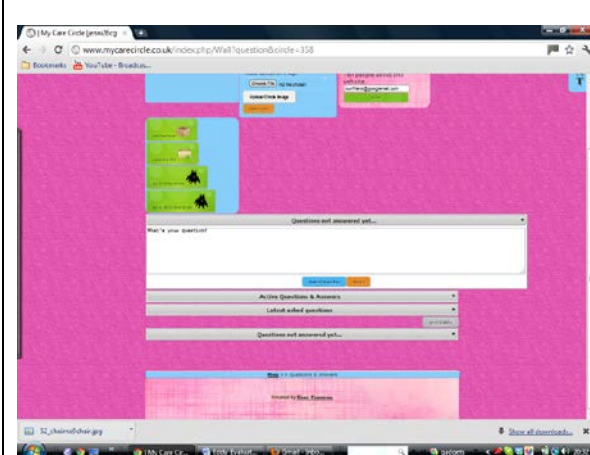
(1)-(4) All three personas submit questions but there is no confirmation if the question has been posted as once 'submitted' it goes back to default screen. This leaves all of them wondering if the question has been submitted.



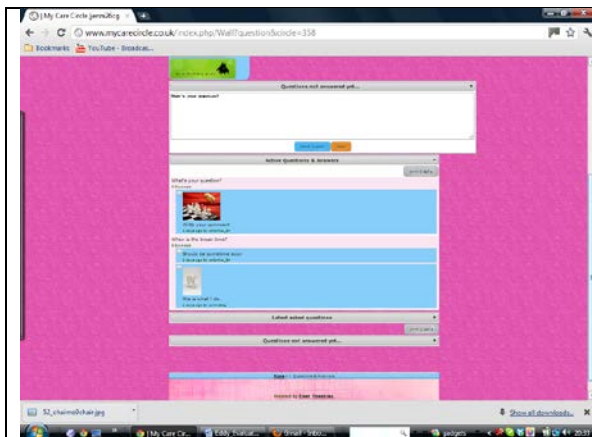
(1)-(4) Comment option is clear to all three personas.



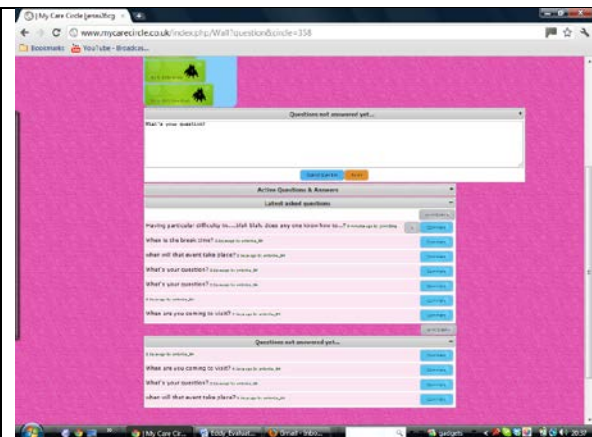
(1)-(4) The option to upload files and comment is clear to all three personas. The image of a person is also misleading to think this could be someone's profile. Also, no option to 'cancel' if you change your mind about commenting. It also allows you to post comments with no content.



(1)-(4) There appears to be a print option for only the latest questions asked. This should also be available for other tasks.



(1)-(4) All three personas found the presentation of Q & A clear. It was noted that there is Print Option.

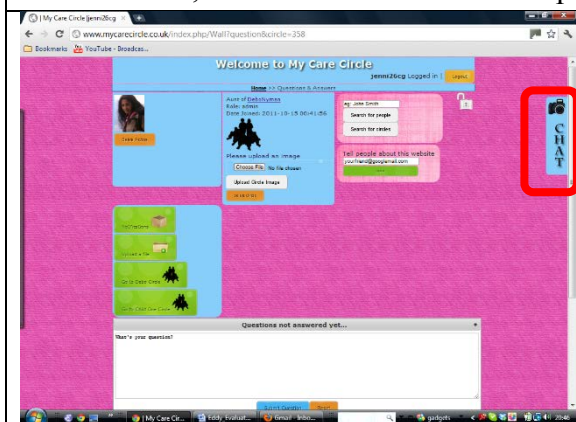


(1)-(4) All personas note that there is a 'Print' option above the bottom Q & A section. It is clear that the print option for the Q & A section just above is in the wrong place and needs to be moved above that section.

4. Progress or status updates for/on your child

This feature has not been implemented.

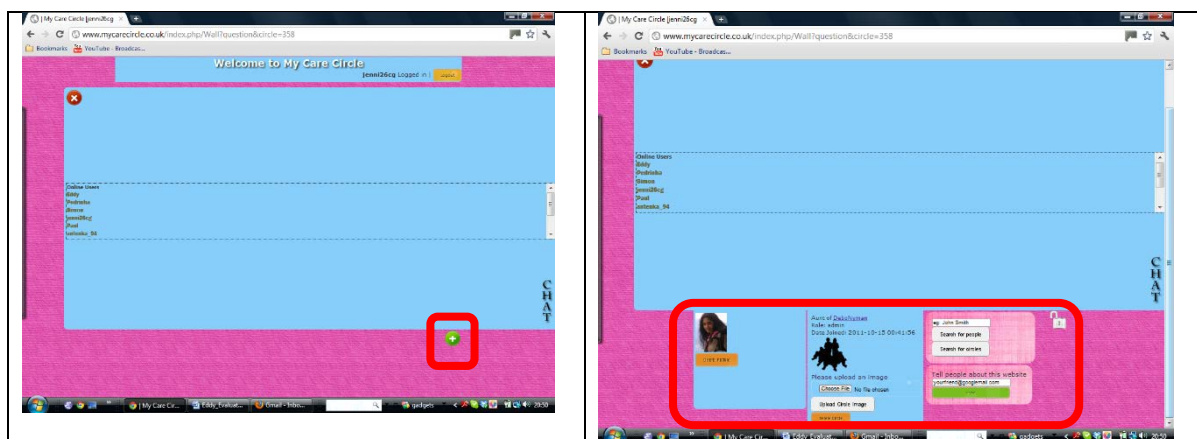
5. Have text, voice or video based chat options where records are not held



(1)-(4) All three personas noted the option to video chat that appears on all pages.

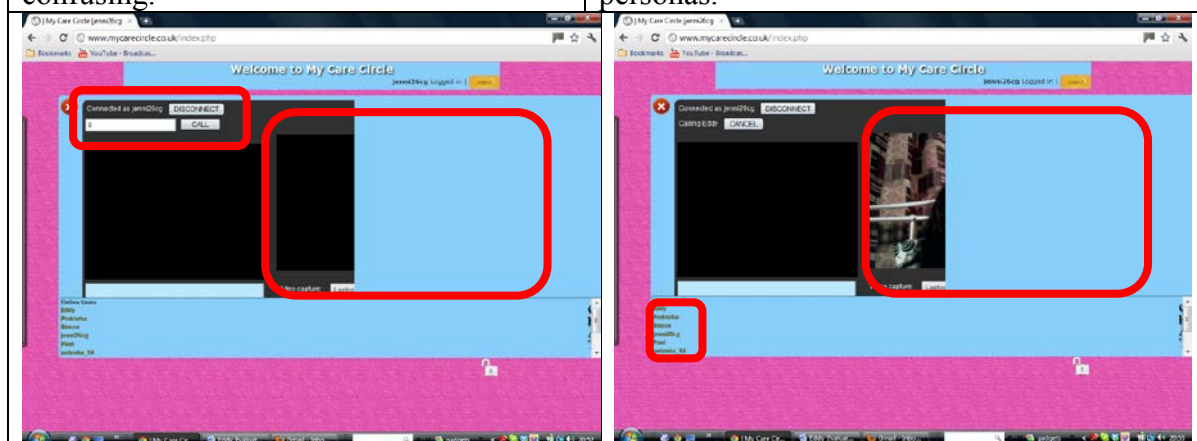


(1)-(4) Once the icon is clicked, the page that appears is incoherent. The lock does not make sense and is confusing. Scroll bar provides list of contacts but it is unclear what needs to be done. This is the same for all 3 personas.



(1)-(4) When the lock was clicked by the personas, a + sign appears. This did not make any sense. The lock icon was also confusing.

(1)-(4) When the + sign was clicked, the top half of other pages appear. This is very confusing and do not make sense to any of the personas.



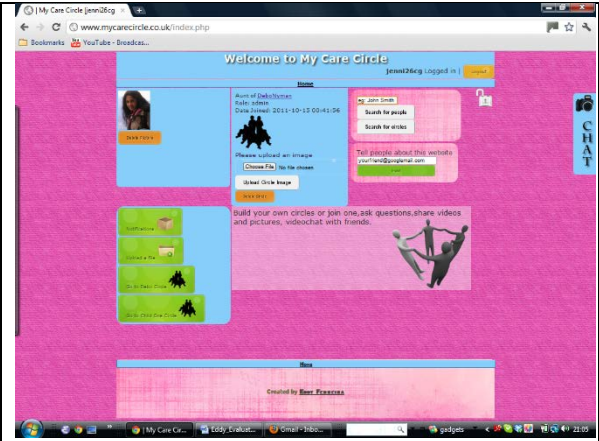
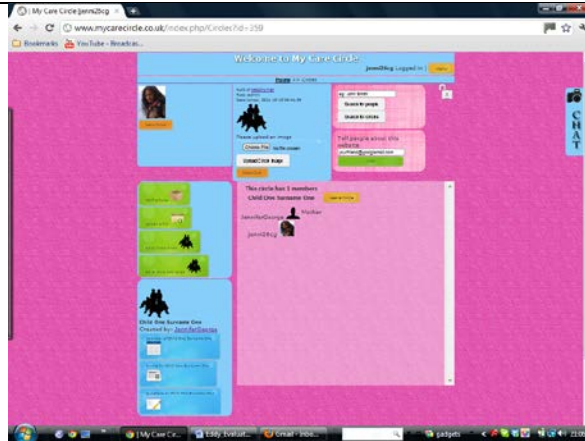
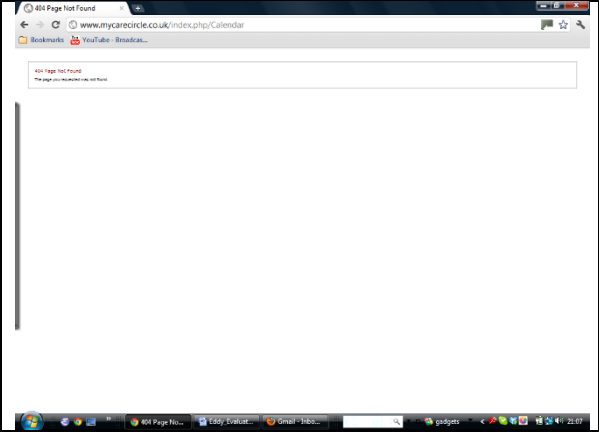
The personas try navigating to the video chat feature from Home page. The result is slightly better but Lock still appears and video also appears. The option to disconnect appears even before being connected. Not sure why '8' has been used as default dial number/ID. The hidden 'CHAT' is also confusing. Only half of the video appears. This failed all questions (1)-(4).

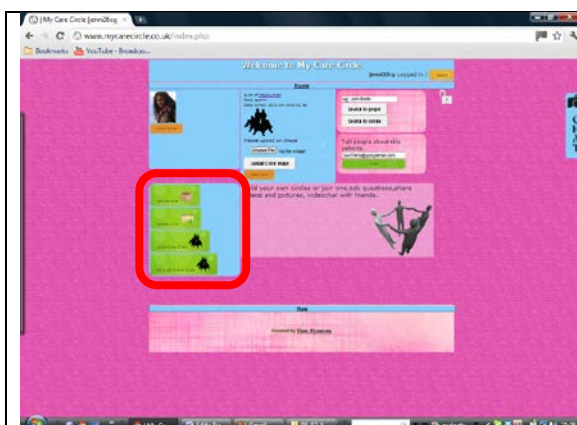
When 'CALL' is used to dial, the video connects but the difference between 'CANCEL' and 'DISCONNECT' is unclear. The personas do not know they are dialling but can see themselves on the video partially. None of the questions (1)-(4) could be answered positively.

6. Follow up online assessments

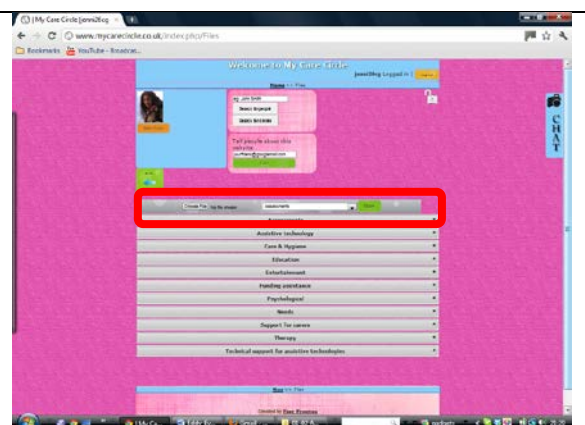
This feature has not been implemented.

7. Calendar with important dates

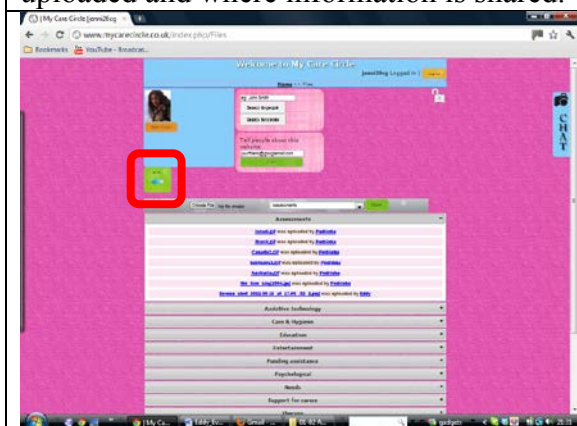
	
<p>(1)-(4) None of the personas could find or navigate to the Calendar from the home page as there was no visible link to it.</p>	<p>(1)-(4) When the care circle was clicked, the Calendar was displayed underneath. However, unless the site resolution is reduced, the calendar cannot be seen as the calendar is placed outside the screen. If the user does not reduce the resolution, the calendar would be visible if the user scrolled down (bug).</p>
	
<p>When calendar is clicked, it returned an Error 404 message. Therefore questions (1)-(4) could not be answered positively.</p>	
<p>8. All users should be able to share files with helpful information</p> <ul style="list-style-type: none"> - Assessments - Assistive technology - Care and Hygiene - Education - Entertainment - Funding assistance - Psychological Needs - Support for carers - Therapy - Technical support for assistive technologies 	



(1)-(4) There is a clear indication to all personas as to where information could be uploaded and where information is shared.



(1)-(4) The instructions are clear to all personas for sharing information.



(1)-(4) The personas find a back button to get back to Home page. This could be replaced with a care circle icon. It is also unclear if this is to be seen only by the care circle members or by all members of the website. There should be a way to indicate who else views this page or provide a warning to say all registered users of the site can view the content.

9. Should be able to view previous records of child

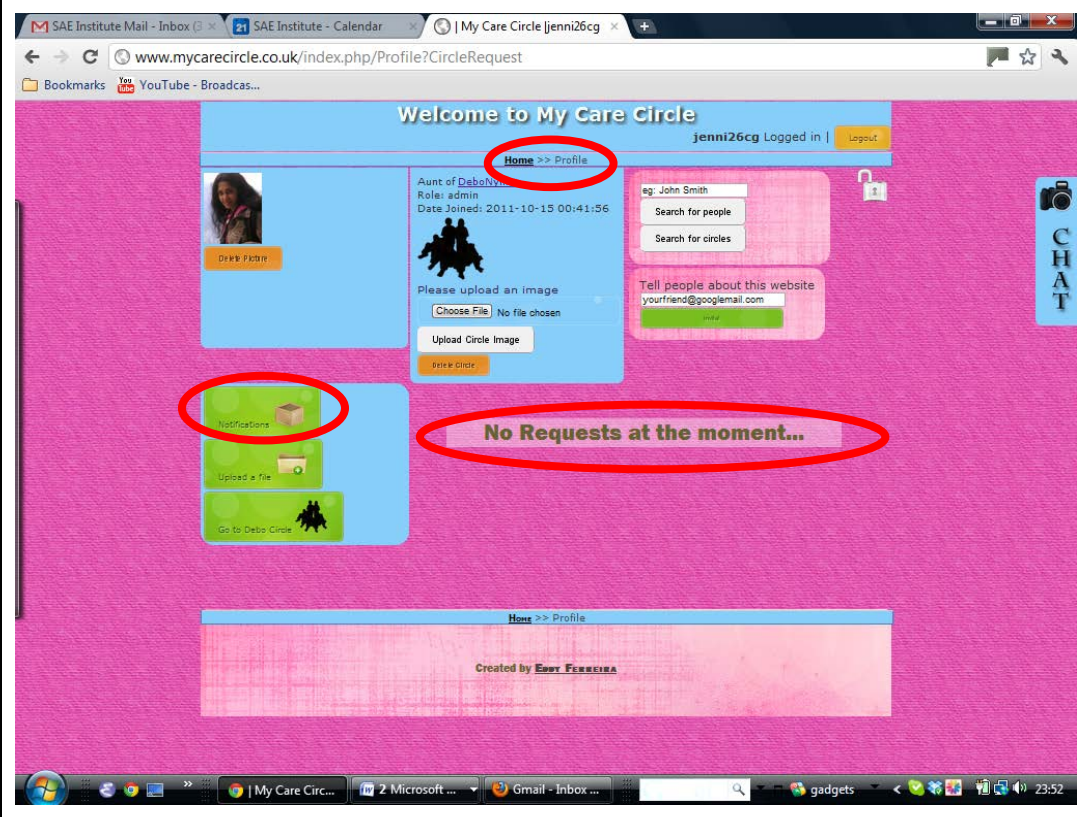
This feature has not been implemented.



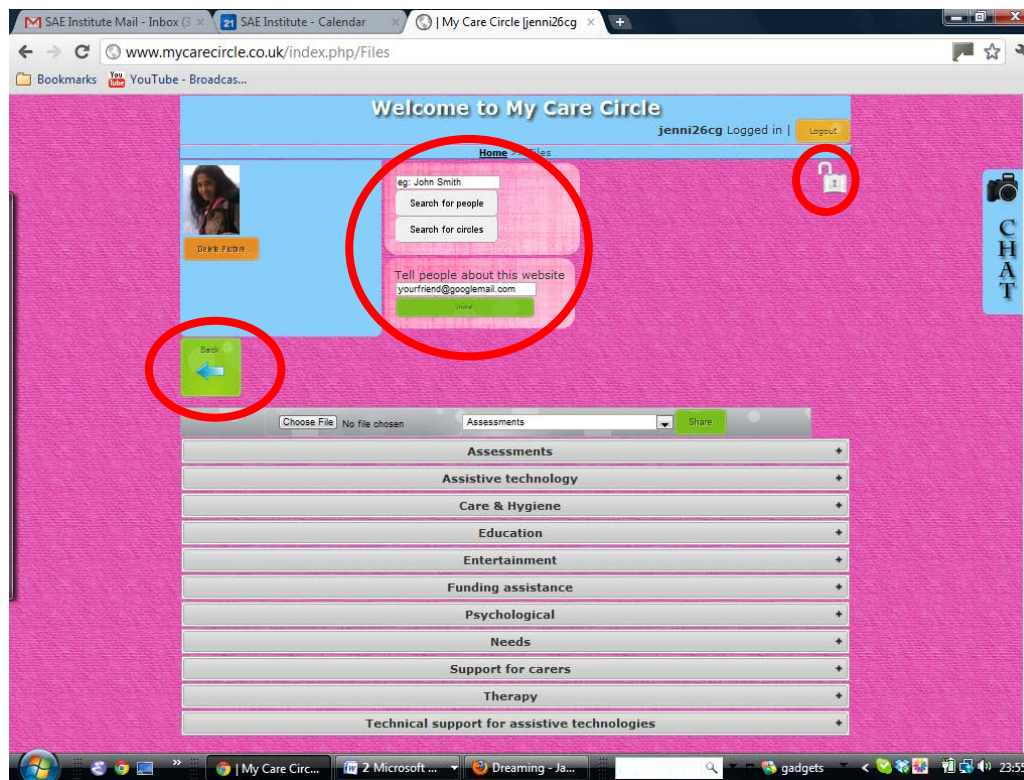
Heuristic Evaluation - A System Checklist

1. Visibility of System Status

The system should always keep user informed about what is going on, through appropriate feedback within reasonable time.

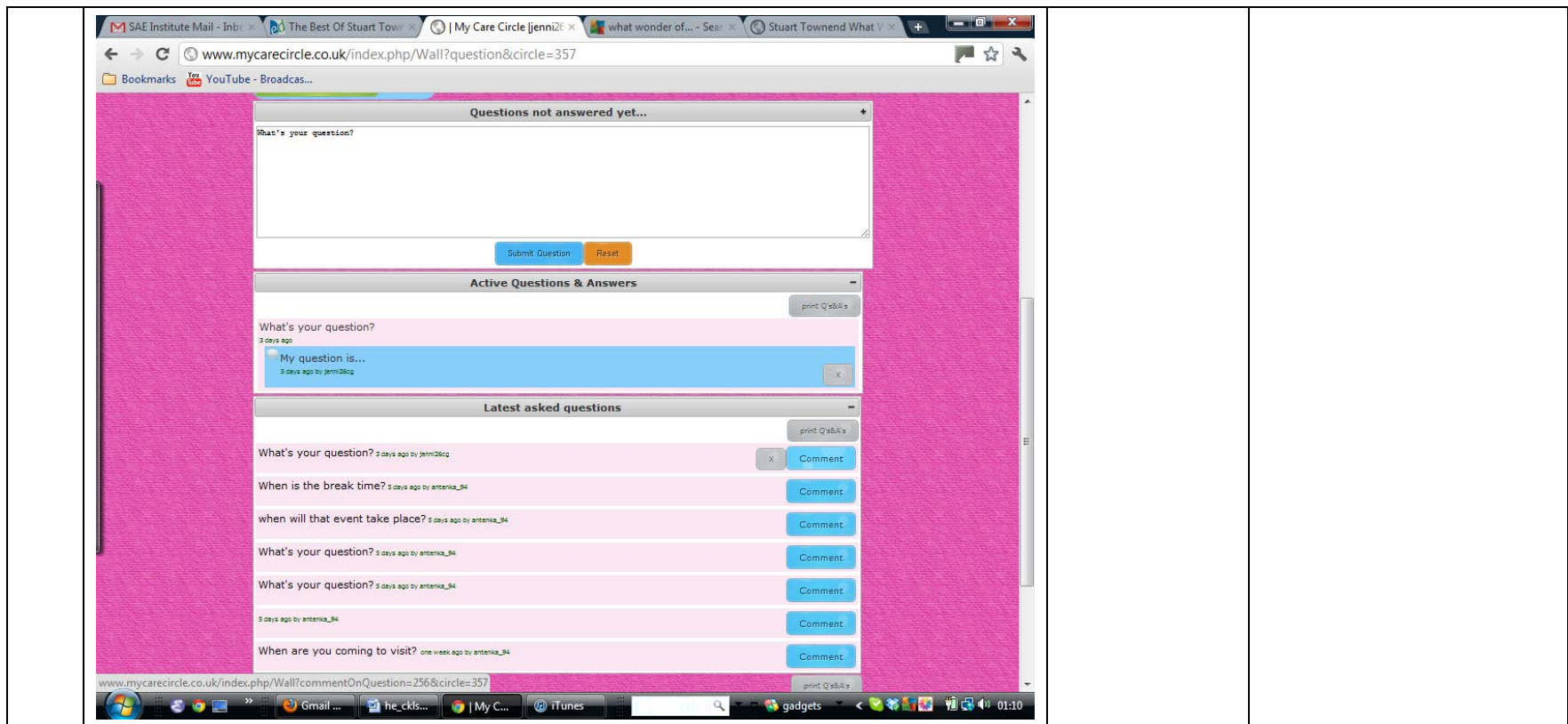
#	Review Checklist	Yes	No	N/A	Comments
1.1	Does every display begin with a title or header that describes screen contents?	O	X	O	
	<p>Bread crumbs are visible most of the time to indicate which page you are on. Events and Notification pages don't indicate this.</p> 				

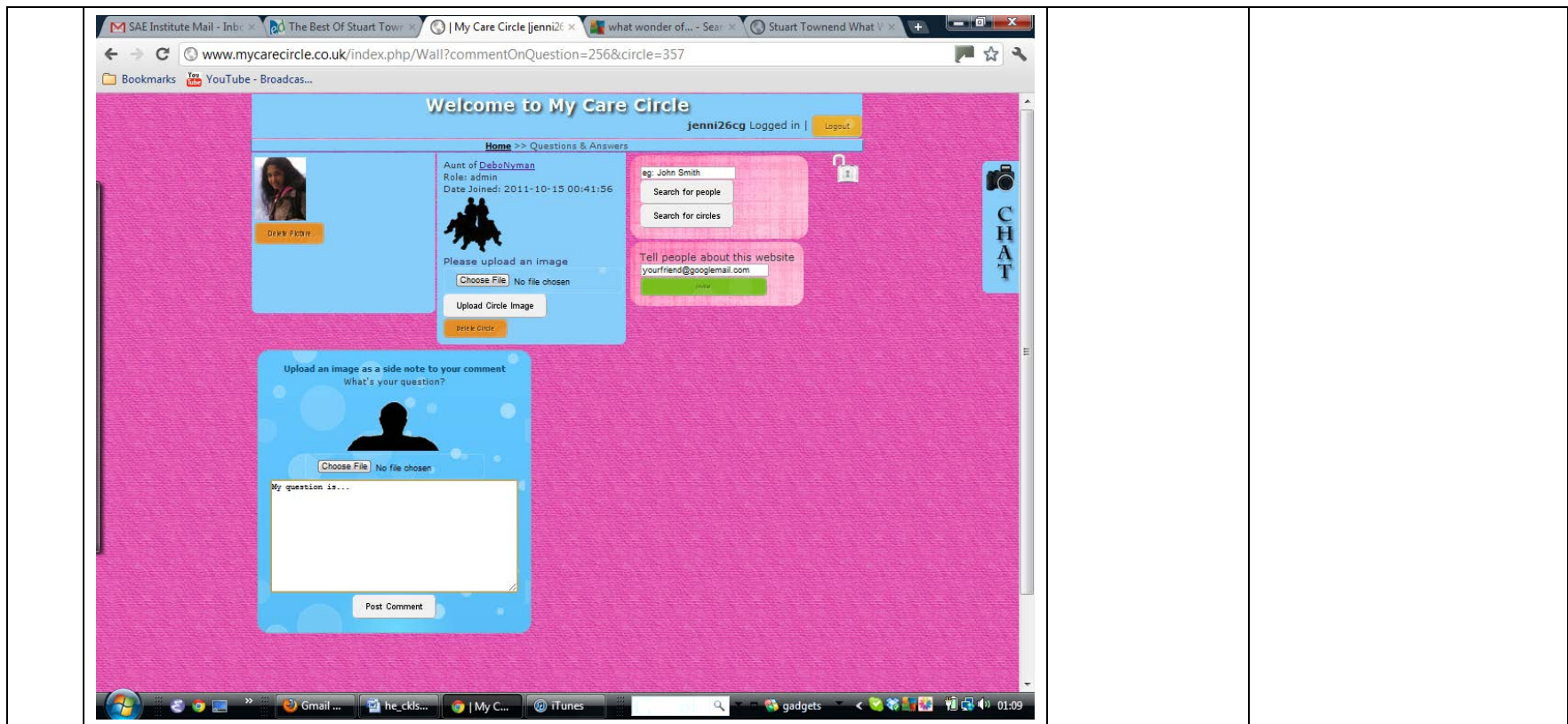
If 'Event's link is clicked, it displays Home Page.

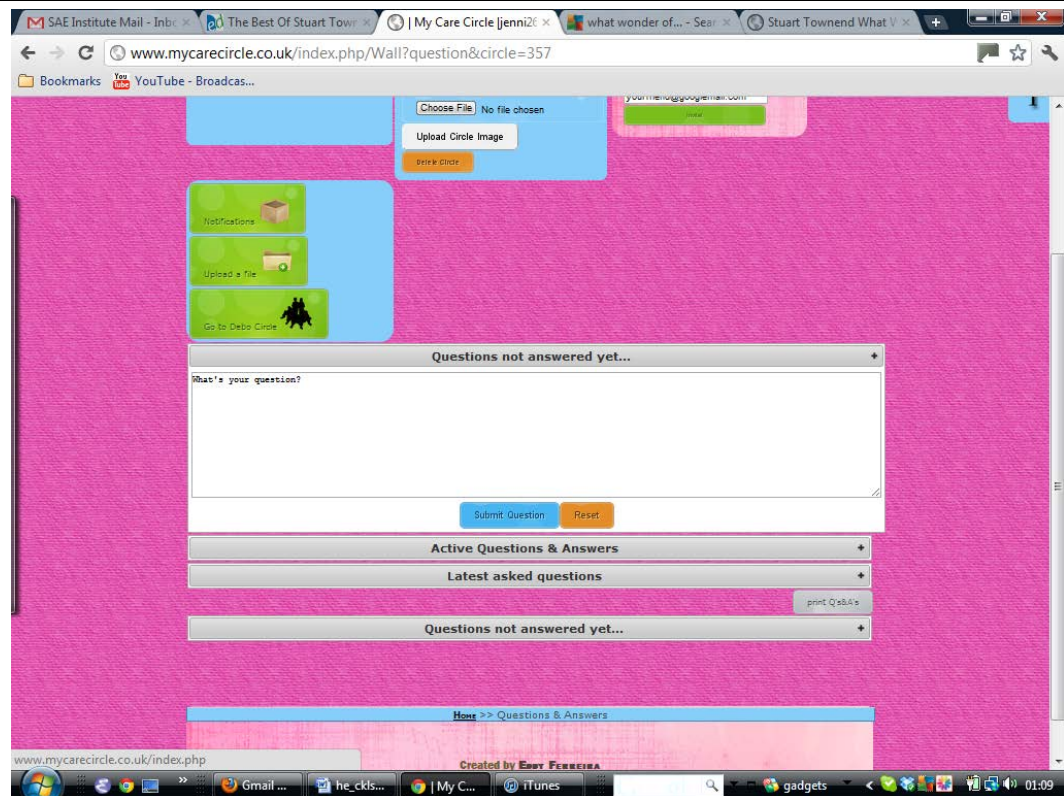


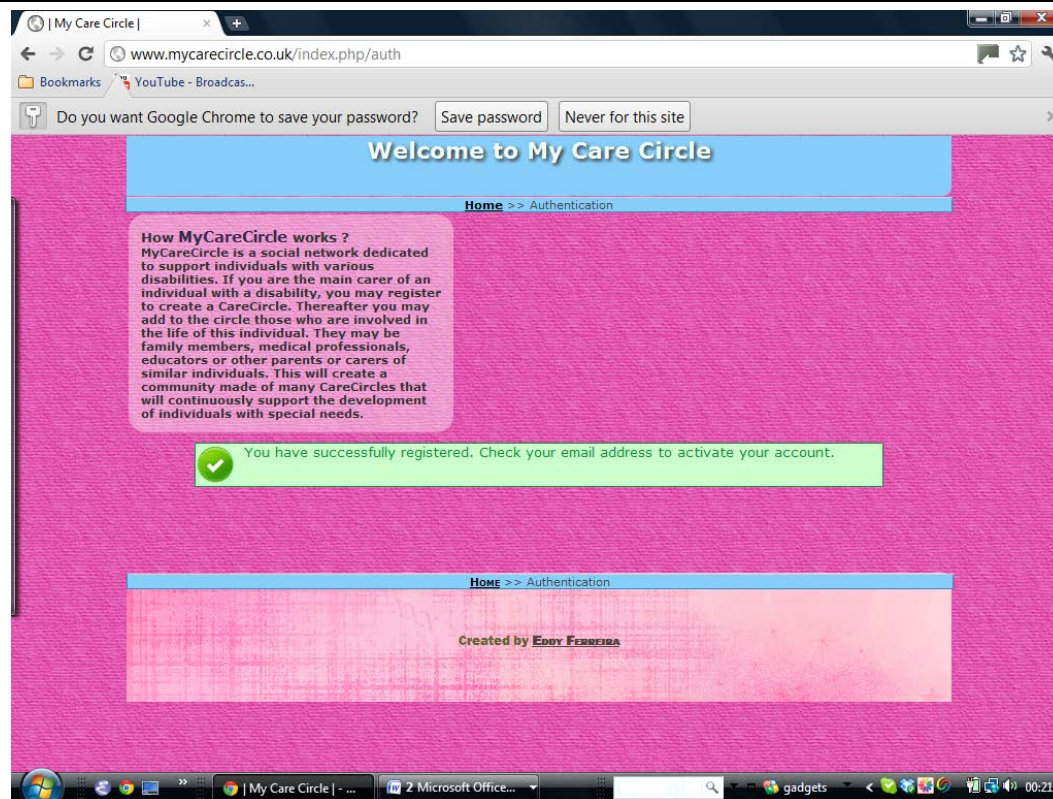
The Upload page has no indication that the care circle information missing. This may be to indicate that the information on this page is not CareCircle specific but this is not indicated.

1.2	Is there a consistent icon design scheme and stylistic treatment across the system?	O	X	O	
	The use of the back button is only on the upload page. It is unclear what this means. The usage of lock icon on all pages is unclear.				
1.3	Is a single, selected icon clearly visible when surrounded by unselected icons?	O	X	O	
	There is no indication that there are three further options if the CareCircle is selected.				
1.4	Do menu instructions, prompts, and error messages appear in the same place(s) on each menu?	O	X	O	
1.5	In multipage data entry screens, is each page labeled to show its relation to others?	O	X	O	
	Posting Q & A the pages don't indicate the steps or confirm that response has been posted.				

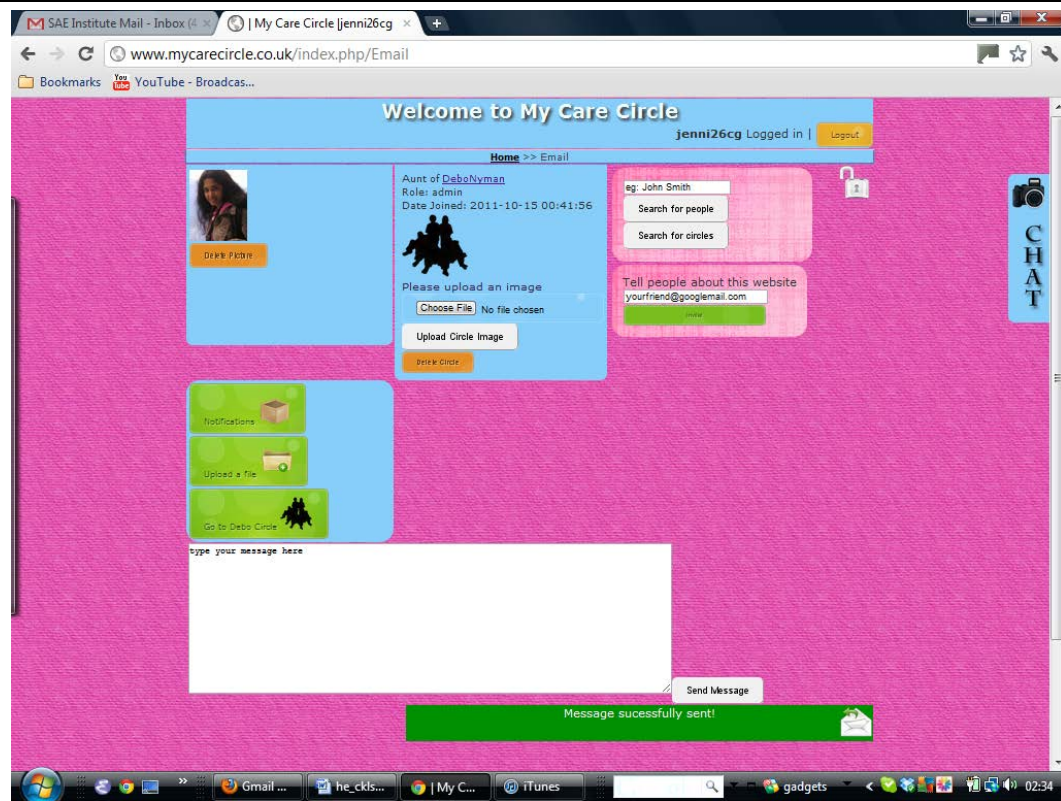




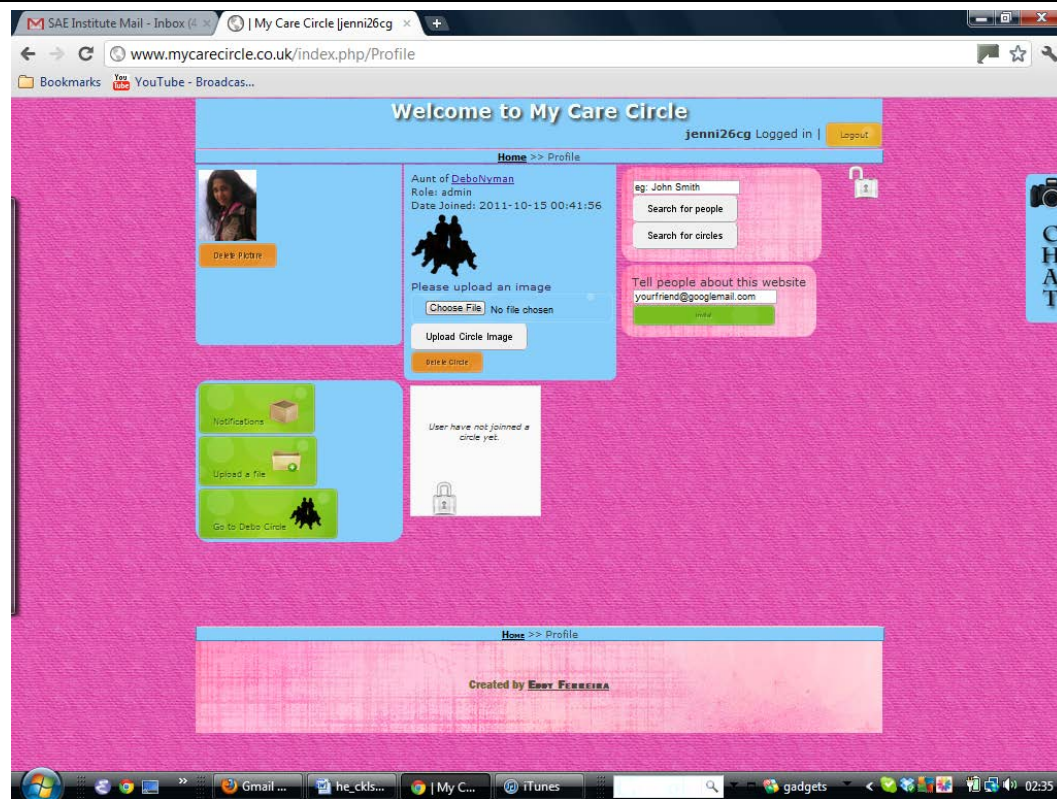
					
1.6	If ovrtype and insert mode are both available, is there a visible indication of which one the user is in?	O	X	O	
	There is inconsistent use of ovrtype and insert text throughout.				
1.7	If pop-up windows are used to display error messages, do they allow the user to see the field in error?	X	O	O	
1.8	Is there some form of system feedback for every operator action?	O	X	O	
	See 1.5, there is no confirmation in this. The following is the confirmation for registering. Except for alignment, this is ok.				



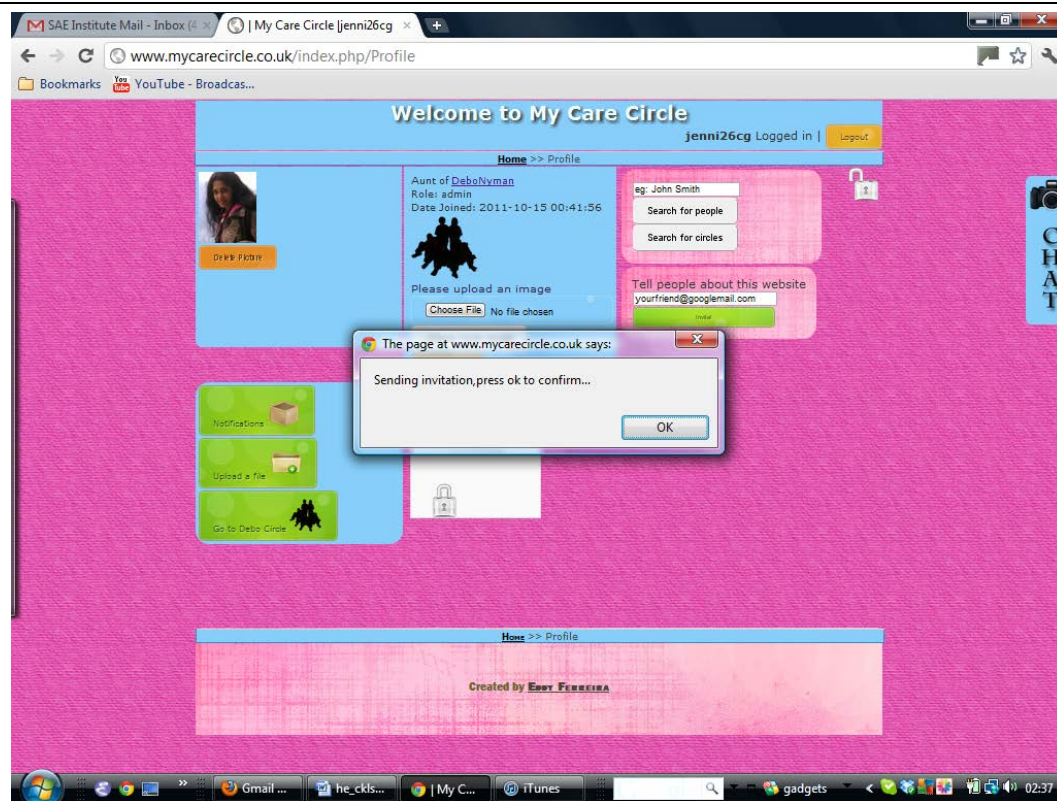
There is confirmation for sending message.



There is a confusingly different message for inviting to Care Circle.

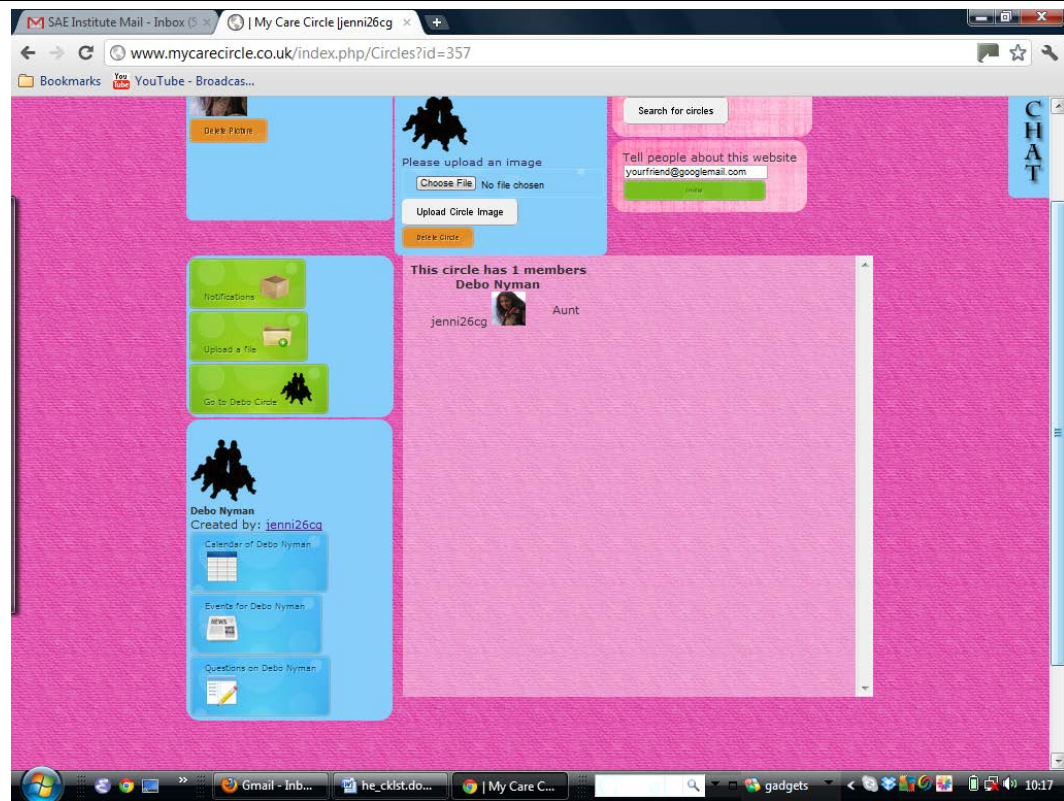


Inviting to CareCircle gives a further different feedback with pop up box.



Uploads don't provide any confirmation for uploading.


1.9	After the user completes an action (or group of actions), does the feedback indicate that the next group of actions can be started?	X	O	O	
1.10	Is there visual feedback in menus or dialog boxes about which choices are selectable?	O	X	O	
	Unless the Care Circle is selected, the options are not available. This is not indicated in anyway.				

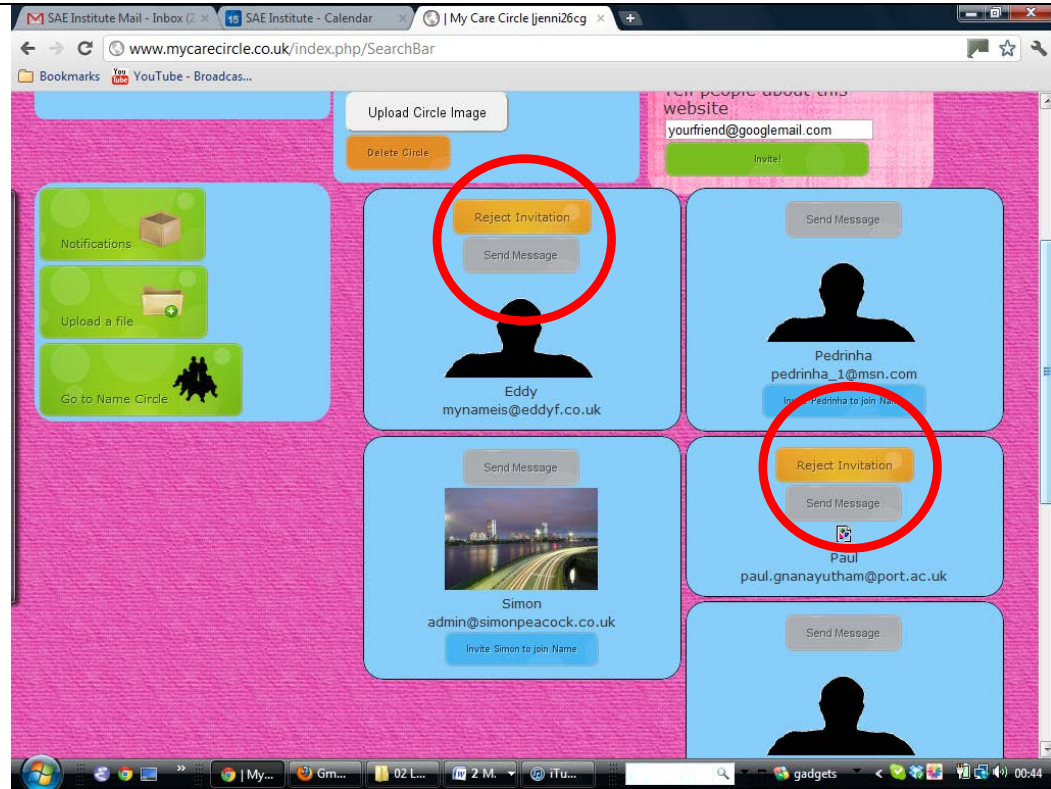
					
1.11	Is there visual feedback in menus or dialog boxes about which choice the cursor is on now?	X	O	O	
1.12	If multiple options can be selected in a menu or dialog box, is there visual feedback about which options are already selected?	O	O	X	
1.13	Is there visual feedback when objects are selected or moved?	O	X	O	
1.14	Is the current status of an icon clearly indicated?	O	X	O	

#	Review Checklist	Yes	No	N/A	Comments
1.15	Is there feedback when function keys are pressed?	O	O	X	
1.16	If there are observable delays (greater than fifteen seconds) in the system's response time, is the user kept informed of the system's progress?	O	X	O	
	The only time this is applicable is during uploads of images or information.				
1.17	Are response times appropriate to the task?	X	O	O	
1.18	Typing, cursor motion, mouse selection: 50-1 50 milliseconds	X	O	O	
1.19	Simple, frequent tasks: less than 1 second	X	O	O	
1.20	Common tasks: 2-4 seconds	X	O	O	
1.21	Complex tasks: 8-12 seconds	X	O	O	
1.22	Are response times appropriate to the user's cognitive processing?	O	X	O	
	This may cause severe delays or inability to complete tasks 1.19-1.21				
1.23	Continuity of thinking is required and information must be remembered throughout several responses: less than two seconds.	X	O	O	
1.24	High levels of concentration aren't necessary and remembering information is not required: two to fifteen seconds.	X	O	O	
1.25	Is the menu-naming terminology consistent with the user's task domain?	O	X	O	
	This is largely ok. 'Upload' should be changed to 'Share' or something that indicates the purpose. CareCircle (name) should indicate what would happen if you clicked on it. The text that explains the functions should be clearer.				
1.26	Does the system provide <i>visibility</i> : that is, by looking, can the user tell the state of the system and the alternatives for action?	X	O	O	
1.27	Do GUI menus make obvious which item has been selected?	O	X	O	
1.28	Do GUI menus make obvious whether deselection is possible?	O	X	O	
1.29	If users must navigate between multiple screens, does the system use context labels, menu maps, and place markers as navigational aids?	O	X	O	

2. Match Between System and the Real World

The system should speak the user's language, with words, phrases and concepts familiar to the user, rather than system-oriented terms. Follow real-world conventions, making information appear in a natural and logical order.

#	Review Checklist	Yes	No	N/A	Comments
2.1	Are icons concrete and familiar?	O	X	O	
	Except for the  icons are familiar.				
2.2	Are menu choices ordered in the most logical way, given the user, the item names, and the task variables?	X	O	O	
2.3	If there is a natural sequence to menu choices, has it been used?	O	O	X	
2.4	Do related and interdependent fields appear on the same screen?	O	X	O	
	The Upload page that leads to 'Share' is quite confusing.				
2.5	If shape is used as a visual cue, does it match cultural conventions?	O	O	X	
2.6	Do the selected colors correspond to common expectations about color codes?	O	O	X	
2.7	When prompts imply a necessary action, are the words in the message consistent with that action?	O	O	X	
2.8	Do keystroke references in prompts match actual key names?	O	O	X	
2.9	On data entry screens, are tasks described in terminology familiar to users?	O	X	O	

					
2.10	Are field-level prompts provided for data entry screens?	O	X	O	
	Guidance on Naming Care Circle should be helpful. i.e. If a mistake is made, it does not provide an option to edit the name.				
2.11	For question and answer interfaces, are questions stated in clear, simple language?	O	O	X	
2.12	Do menu choices fit logically into categories that have readily understood meanings?	O	O	X	
2.13	Are menu titles parallel grammatically?	O	O	X	
2.14	Does the command language employ user jargon and avoid computer jargon?	O	X	O	
	Use 'Share' instead of 'Upload'				
2.15	Are command names specific rather than general?	O	O	X	
2.16	Does the command language allow both full names and abbreviations?	O	O	X	
2.17	Are input data codes meaningful?	O	O	X	
2.18	Have uncommon letter sequences been avoided whenever possible?	O	O	X	

2.19	Does the system automatically enter leading or trailing spaces to align decimal points?	O	O	X	
2.20	Does the system automatically enter a dollar sign and decimal for monetary entries?	O	O	X	
2.21	Does the system automatically enter commas in numeric values greater than 9999?	O	O	X	
2.22	Do GUI menus offer activation: that is, make obvious how to say <i>"now do it"</i> ?	O	O	X	
2.23	Has the system been designed so that keys with similar names do not perform opposite (and potentially dangerous) actions?	O	O	X	
2.24	Are function keys labeled clearly and distinctively, even if this means breaking consistency rules?	O	O	X	

3. User Control and Freedom


Users should be free to select and sequence tasks (when appropriate), rather than having the system do this for them. Users often choose system functions by mistake and will need a clearly marked “emergency exit” to leave the unwanted state without having to go through an extended dialogue. Users should make their own decisions (with clear information) regarding the costs of exiting current work. The system should support undo and redo.

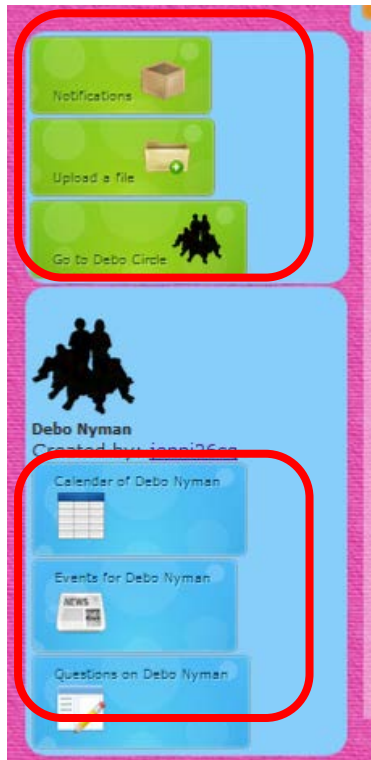
#	Review Checklist	Yes	No	N/A	Comments
3.1	If setting up windows is a low-frequency task, is it particularly easy to remember?	O	O	X	
3.2	In systems that use overlapping windows, is it easy for users to rearrange windows on the screen?	O	O	X	
3.3	In systems that use overlapping windows, is it easy for users to switch between windows?	O	O	X	
3.4	When a user's task is complete, does the system wait for a signal from the user before processing?	X	O	O	
3.5	Can users type-ahead in a system with many nested menus?	O	O	X	
3.6	Are users prompted to confirm commands that have drastic, destructive consequences?	O	O	X	
3.7	Is there an "undo" function at the level of a single action, a data entry, and a complete group of actions?	O	X	O	
3.8	Can users cancel out of operations in progress?	O	X	O	
3.9	Are character edits allowed in commands?	O	O	X	
3.10	Can users reduce data entry time by copying and modifying existing data?	O	O	X	
3.11	Are character edits allowed in data entry fields?	O	X	O	
3.12	If menu lists are long (more than seven items), can users select an item either by moving the cursor or by typing a mnemonic code?	O	O	X	
3.13	If the system uses a pointing device, do users have the option of either clicking on menu items or using a keyboard shortcut?	O	O	X	
3.14	Are menus broad (many items on a menu) rather than deep (many menu levels)?	X	O	O	
3.15	If the system has multiple menu levels, is there a mechanism that allows users to go back to previous menus?	X	O	O	

#	Review Checklist	Yes	No	N/A	Comments
3.16	If users can go back to a previous menu, can they change their earlier menu choice?	O	O	X	
3.17	Can users move forward and backward between fields or dialog box options?	X	O	O	
3.18	If the system has multipage data entry screens, can users move backward and forward among all the pages in the set?	O	O	X	
3.19	If the system uses a question and answer interface, can users go back to previous questions or skip forward to later questions?	O	O	X	
3.20	Do function keys that can cause serious consequences have an undo feature?	O	O	X	
3.21	Can users easily reverse their actions?	O	X	O	
3.22	If the system allows users to reverse their actions, is there a retracing mechanism to allow for multiple undos?	O	O	X	
3.23	Can users set their own system, session, file, and screen defaults?	O	O	X	

4. Consistency and Standards

Users should not have to wonder whether different words, situations, or actions mean the same thing. Follow platform conventions.

#	Review Checklist	Yes	No	N/A	Comments
4.1	Have industry or company formatting standards been followed consistently in all screens within a system?	O	X	O	
	Lacks alignment in many places in the design				
4.2	Has a heavy use of all uppercase letters on a screen been avoided?	X	O	O	
4.3	Do abbreviations not include punctuation?	O	O	X	
4.4	Are integers right-justified and real numbers decimal-aligned?	O	O	X	
4.5	Are icons labeled?	O	X	O	
	Except for  , all icons are labeled.				
4.6	Are there no more than twelve to twenty icon types?	X	O	O	
4.7	Are there salient visual cues to identify the active window?	O	X	O	
4.8	Does each window have a title?	O	X	O	
4.9	Are vertical and horizontal scrolling possible in each window?	X	O	O	
4.10	Does the menu structure match the task structure?	X	O	O	
4.11	Have industry or company standards been established for menu design, and are they applied consistently on all menu screens in the system?	O	O	X	
4.12	Are menu choice lists presented vertically?	X	O	O	
4.13	If "exit" is a menu choice, does it always appear at the bottom of the list?	O	O	X	
4.14	Are menu titles either centered or left-justified?	X	O	O	
4.15	Are menu items left-justified, with the item number or mnemonic preceding the name?	O	O	X	
4.16	Do embedded field-level prompts appear to the right of the field label?	O	O	X	
4.17	Do on-line instructions appear in a consistent location across screens?	O	X	O	

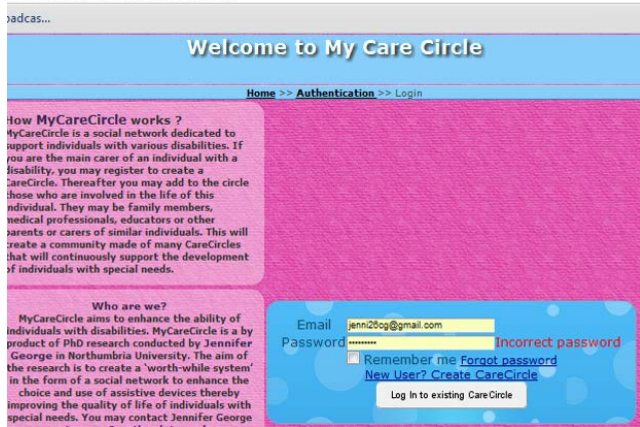
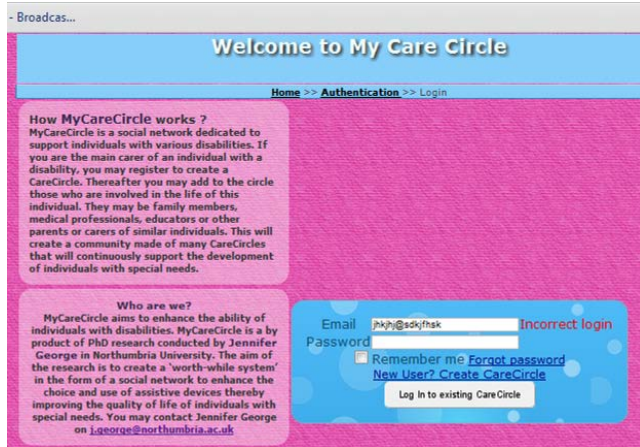
	 <p>Text should consistently appear left bottom of buttons.</p>				
4.18	Are field labels and fields distinguished typographically?	X	O	O	
4.19	Are field labels consistent from one data entry screen to another?	O	O	X	
4.20	Are fields and labels left-justified for alpha lists and right-justified for numeric lists?	O	O	X	

#	Review Checklist	Yes	No	N/A	Comments
4.21	Do field labels appear to the left of single fields and above list fields?	O	O	X	
4.22	Are attention-getting techniques used with care?	O	O	X	
4.23	Intensity: two levels only	X	O	O	
4.24	Size: up to four sizes	O	O	X	
4.25	Font: up to three	O	X	O	
	More control of font size would be beneficial. Some font too small.				
4.26	Blink: two to four hertz	O	O	X	
4.27	Color: up to four (additional colors for occasional use only)	O	X	O	
	Could replace text background with white.				
4.28	Sound: soft tones for regular positive feedback, harsh for rare critical conditions	O	O	X	
4.29	Are attention-getting techniques used only for exceptional conditions or for time-dependent information?	O	O	X	
4.30	Are there no more than four to seven colors, and are they far apart along the visible spectrum?	X	O	O	
4.31	Is a legend provided if color codes are numerous or not obvious in meaning?	O	O	X	
4.32	Have pairings of high-chroma, spectrally extreme colors been avoided?	X	O	O	
4.33	Are saturated blues avoided for text or other small, thin line symbols?	X	O	O	
4.34	Is the most important information placed at the beginning of the prompt?	X	O	O	
4.35	Are user actions named consistently across all prompts in the system?	O	O	X	
4.36	Are system objects named consistently across all prompts in the system?	O	O	X	
4.37	Do field-level prompts provide more information than a restatement of the field name?	O	O	X	
4.38	For question and answer interfaces, are the valid inputs for a question listed?	O	O	X	
4.39	Are menu choice names consistent, both within each menu and across the system, in grammatical style and terminology?	O	O	X	
4.40	Does the structure of menu choice names match their corresponding menu titles?	O	O	X	
4.41	Are commands used the same way, and do they mean the same thing, in all parts of the system?	O	O	X	
4.42	Does the command language have a consistent, natural, and mnemonic syntax?	O	O	X	
4.43	Do abbreviations follow a simple primary rule and, if necessary, a simple secondary rule for abbreviations that otherwise would be duplicates?	O	O	X	

#	Review Checklist	Yes	No	N/A	Comments
4.44	Is the secondary rule used only when necessary?	O	O	X	
4.45	Are abbreviated words all the same length?	O	O	X	
4.46	Is the structure of a data entry value consistent from screen to screen?	O	O	X	
4.47	Is the method for moving the cursor to the next or previous field consistent throughout the system?	O	O	X	
4.48	If the system has multipage data entry screens, do all pages have the same title?	O	O	X	
4.49	If the system has multipage data entry screens, does each page have a sequential page number?	O	O	X	
4.50	Does the system follow industry or company standards for function key assignments?	O	O	X	
4.51	Are high-value, high-chroma colors used to attract attention?	O	O	X	

5. Help Users Recognize, Diagnose, and Recover From Errors

Error messages should be expressed in plain language (NO CODES).

#	Review Checklist	Yes	No	N/A	Comments
5.1	Is sound used to signal an error?	O	O	X	
5.2	Are prompts stated constructively, without overt or implied criticism of the user?	O	O	O	
	<p>ecircle.co.uk/index.php/auth/login</p>  <p>The screenshot shows the login page of MyCareCircle. The page has a blue header with the title 'Welcome to My Care Circle' and a breadcrumb trail 'Home >> Authentication >> Login'. Below the header, there is a pink sidebar with text explaining how MyCareCircle works and who they are. The main content area is blue and contains a login form. The form has fields for 'Email' (jenn200@gmail.com) and 'Password' (*****). Below the password field, there is a red error message 'Incorrect password'. There are also links for 'Remember me', 'Forgot password', 'New User? Create CareCircle', and a 'Log In to existing CareCircle' button.</p> <p>- Broadcas...</p>  <p>The screenshot shows the same login page as above, but with a different email address 'jhp@skyfhsk' entered in the email field. The error message now says 'Incorrect login' in red. The rest of the page layout and text are identical to the previous screenshot.</p>				

SAE Institute - Calendar | My Care Circle

mycarecircle.co.uk/index.php/auth/login

e - Broadcas...

Welcome to My Care Circle

Home >> Authentication >> Login

How MyCareCircle works ?
MyCareCircle is a social network dedicated to support individuals with various disabilities. If you are the main carer of an individual with a disability, you may register to create a CareCircle. Thereafter you may add to the circle those who are involved in the life of this individual. They may be family members, medical professionals, educators or other parents or carers of similar individuals. This will create a community made of many CareCircles that will continuously support the development of individuals with special needs.

Who are we?
MyCareCircle aims to enhance the ability of individuals with disabilities. MyCareCircle is a by product of PhD research conducted by Jennifer George in Northumbria University. The aim of the research is to create a 'worth-while system' in the form of a social network to enhance the choice and use of assistive devices thereby improving the quality of life of individuals with special needs. You may contact Jennifer George on j.george@northumbria.ac.uk

Email:

Password: The Password field is required.

☐ Remember me [Forgot password](#)
[New User? Create CareCircle](#)

Welcome to My Care Circle

Home >> Authentication >> Register

How MyCareCircle works ?
MyCareCircle is a social network dedicated to support individuals with various disabilities. If you are the main carer of an individual with a disability, you may register to create a CareCircle. Thereafter you may add to the circle those who are involved in the life of this individual. They may be family members, medical professionals, educators or other parents or carers of similar individuals. This will create a community made of many CareCircles that will continuously support the development of individuals with special needs.

STEP 1
You are about to create a new user

Name:

Email Address:


Password:

Confirm Password:

The Email field must contain a valid email address.

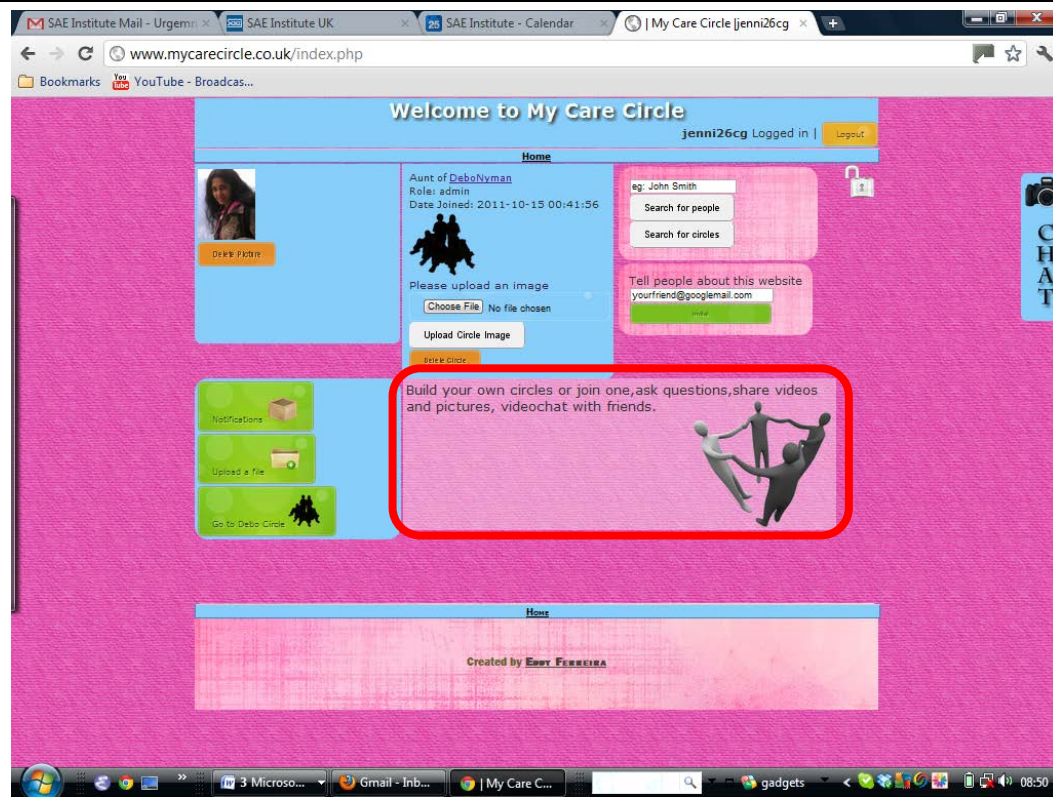
The Confirm Password field does not match the Password field.

STEP 2



Polite instructions. It is unclear why when password is not typed, the box jumps to the bottom. The registration error messages are centre aligned unlike the other messages.

5.3	Do prompts imply that the user is in control?	O	O	O
5.4	Are prompts brief and unambiguous.	X	O	O



Text is worded like instructions but doesn't indicate where or how this can be done.

5.5	Are error messages worded so that the system, not the user, takes the blame?	X	O	O	
5.6	If humorous error messages are used, are they appropriate and inoffensive to the user population?	O	O	X	
5.7	Are error messages grammatically correct?	X	O	O	
5.8	Do error messages avoid the use of exclamation points?	X	O	O	
5.9	Do error messages avoid the use of violent or hostile words?	X	O	O	
5.10	Do error messages avoid an anthropomorphic tone?	X	O	O	
5.11	Do all error messages in the system use consistent grammatical style, form, terminology, and abbreviations?	X	O	O	
5.12	Do messages place users in control of the system?	X	O	O	
5.13	Does the command language use normal action-object syntax?	X	O	O	
5.14	Does the command language avoid arbitrary, non-English use of punctuation, except for symbols that users already know?	X	O	O	

5.15	If an error is detected in a data entry field, does the system place the cursor in that field or highlight the error?	X	O	O	
5.16	Do error messages inform the user of the error's severity?	O	O	X	
5.17	Do error messages suggest the cause of the problem?	X	O	O	
5.18	Do error messages provide appropriate semantic information?	O	O	X	
5.19	Do error messages provide appropriate syntactic information?	O	O	X	
5.20	Do error messages indicate what action the user needs to take to correct the error?	X	O	O	
5.21	If the system supports both novice and expert users, are multiple levels of error-message detail available?	O	O	X	

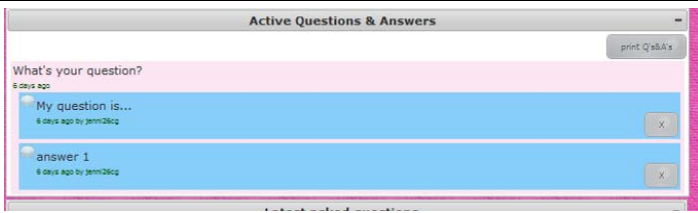
6. Error Prevention

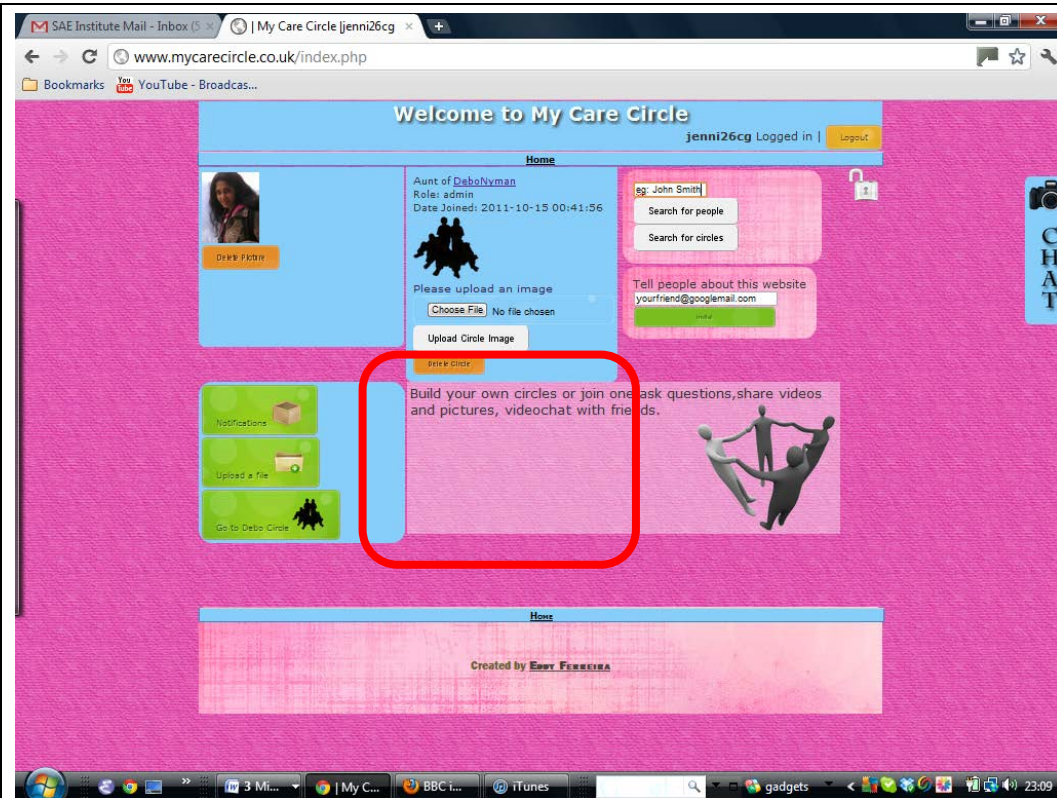
Even better than good error messages is a careful design which prevents a problem from occurring in the first place.

#	Review Checklist	Yes	No	N/A	Comments
6.1	If the database includes groups of data, can users enter more than one group on a single screen?	O	O	X	
6.2	Have dots or underscores been used to indicate field length?	O	O	X	
6.3	Is the menu choice name on a higher-level menu used as the menu title of the lower-level menu?	O	O	X	
6.4	Are menu choices logical, distinctive, and mutually exclusive?	O	O	X	
6.5	Are data inputs case-blind whenever possible?	O	O	X	
6.6	If the system displays multiple windows, is navigation between windows simple and visible?	O	O	X	
6.7	Are the function keys that can cause the most serious consequences in hard-to-reach positions?	O	O	X	
6.8	Are the function keys that can cause the most serious consequences located far away from low-consequence and high-use keys?	O	O	X	
6.9	Has the use of qualifier keys been minimized?	O	O	X	
6.10	If the system uses qualifier keys, are they used consistently throughout the system?	O	O	X	
6.11	Does the system prevent users from making errors whenever possible?	O	O	X	
6.12	Does the system warn users if they are about to make a potentially serious error?	O	X	O	
6.13	Does the system intelligently interpret variations in user commands?	O	O	X	
6.14	Do data entry screens and dialog boxes indicate the number of character spaces available in a field?	O	X	O	
6.15	Do fields in data entry screens and dialog boxes contain default values when appropriate?	O	O	X	

7. Recognition Rather Than Recall


Make objects, actions, and options visible. The user should not have to remember information from one part of the dialogue to another. Instructions for use of the system should be visible or easily retrievable whenever appropriate.

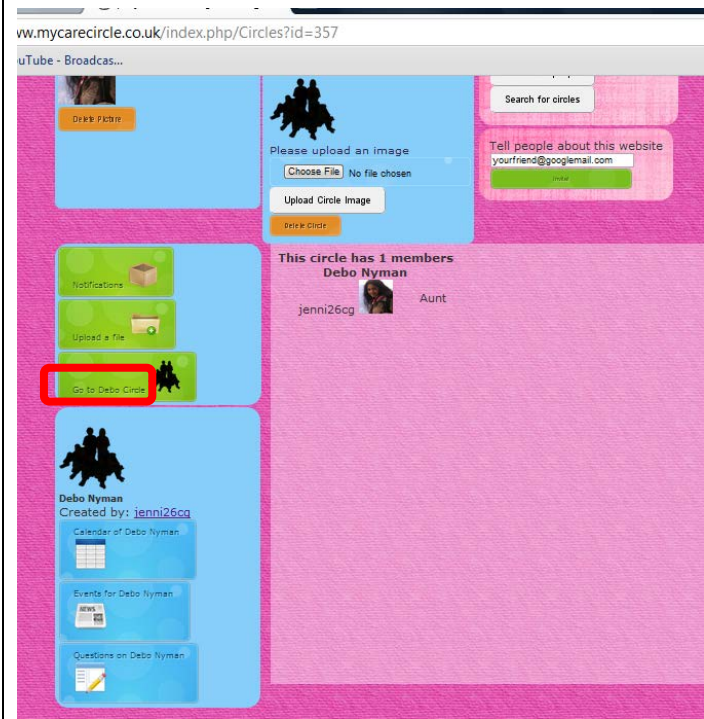
#	Review Checklist	Yes	No	N/A	Comments
7.1	For question and answer interfaces, are visual cues and white space used to distinguish questions, prompts, instructions, and user input?	X	O	O	
					
7.2	Does the data display start in the upper-left corner of the screen?	X	O	O	
7.3	Are multiword field labels placed horizontally (not stacked vertically)?	X	O	O	
7.4	Are all data a user needs on display at each step in a transaction sequence?	X	O	O	
7.5	Are prompts, cues, and messages placed where the eye is likely to be looking on the screen?	X	O	O	
7.6	Have prompts been formatted using white space, justification, and visual cues for easy scanning?	X	O	O	
7.7	Do text areas have "breathing space" around them?	O	X	O	



Uneven space between sections.

7.8	Is there an obvious visual distinction made between "choose one" menu and "choose many" menus?	O	O	X	
7.9	Have spatial relationships between soft function keys (on-screen cues) and keyboard function keys been preserved?	O	O	X	
7.10	Does the system gray out or delete labels of currently inactive soft function keys?	O	O	X	
7.11	Is white space used to create symmetry and lead the eye in the appropriate direction?	O	X	O	
7.12	Have items been grouped into logical zones, and have headings been used to distinguish between zones?	O	O	X	
7.13	Are zones no more than twelve to fourteen characters wide and six to seven lines high?	O	O	X	
7.14	Have zones been separated by spaces, lines, color, letters, bold titles, rules lines, or shaded areas?	O	O	X	
7.15	Are field labels close to fields, but separated by at least one space?	O	X	O	

	 <p>Spacing could be improved</p>				
7.16	Are long columnar fields broken up into groups of five, separated by a blank line?	O	O	X	
7.17	Are optional data entry fields clearly marked?	O	O	X	
7.18	Are symbols used to break long input strings into "chunks"?	O	O	X	
7.19	Is reverse video or color highlighting used to get the user's attention?	O	O	X	
7.20	Is reverse video used to indicate that an item has been selected?	O	O	X	
7.21	Are size, boldface, underlining, color, shading, or typography used to show relative quantity or importance of different screen items?	O	X	O	
7.22	Are borders used to identify meaningful groups?	O	O	X	
7.23	Has the same color been used to group related elements?	X	O	O	
7.24	Is color coding consistent throughout the system?	X	O	O	
7.25	Is color used in conjunction with some other redundant cue?	O	O	X	
7.26	Is there good color and brightness contrast between image and background colors?	X	O	O	
7.27	Have light, bright, saturated colors been used to emphasize data and have darker, duller, and desaturated colors been used to de-emphasize data?	O	X	O	
7.28	Is the first word of each menu choice the most important?	O	X	O	

	 <p>ww.mycarecircle.co.uk/index.php/Circles?id=357</p> <p>uTube - Broadcas...</p> <p>Search for circles</p> <p>Please upload an image</p> <p>Choose File No file chosen</p> <p>Upload Circle Image</p> <p>Rele circle</p> <p>Tell people about this website</p> <p>yourfriend@googlemail.com</p> <p>Notifications</p> <p>Upload a file</p> <p>Go to Debo Circle</p> <p>Debo Nyman</p> <p>Created by: jenni26cg</p> <p>Calendar of Debo Nyman</p> <p>Events for Debo Nyman</p> <p>Questions on Debo Nyman</p> <p>This circle has 1 members</p> <p>Debo Nyman</p> <p>jenni26cg Aunt</p>				
	Except for the 'Go' all other choices are ok				
7.29	Does the system provide <i>mapping</i> : that is, are the relationships between controls and actions apparent to the user?	X	O	O	
7.30	Are input data codes distinctive?	O	O	X	
7.31	Have frequently confused data pairs been eliminated whenever possible?	X	O	O	
7.32	Have large strings of numbers or letters been broken into chunks?	O	O	X	
7.33	Are inactive menu items grayed out or omitted?	O	O	X	
7.34	Are there menu selection defaults?	X	O	O	
7.35	If the system has many menu levels or complex menu levels, do users have access to an on-line spatial menu map?	O	O	X	
7.36	Do GUI menus offer affordance: that is, make obvious where selection is possible?	X	O	O	
7.37	Are there salient visual cues to identify the active window?	O	X	O	
7.38	Are function keys arranged in logical groups?	O	O	X	

7.39	Do data entry screens and dialog boxes indicate when fields are optional?	O	O	X	
7.40	On data entry screens and dialog boxes, are dependent fields displayed only when necessary?	O	O	X	

8. Flexibility and Minimalist Design

Accelerators-unseen by the novice user-may often speed up the interaction for the expert user such that the system can cater to both inexperienced and experienced users. Allow users to tailor frequent actions. Provide alternative means of access and operation for users who differ from the “average” user (e.g., physical or cognitive ability, culture, language, etc.)

#	Review Checklist	Yes	No	N/A	Comments
8.1	If the system supports both novice and expert users, are multiple levels of error message detail available?	O	O	X	
8.2	Does the system allow novices to use a keyword grammar and experts to use a positional grammar?	O	O	X	
8.3	Can users define their own synonyms for commands?	O	O	X	
8.4	Does the system allow novice users to enter the simplest, most common form of each command, and allow expert users to add parameters?	O	O	X	
8.5	Do expert users have the option of entering multiple commands in a single string?	O	O	X	
8.6	Does the system provide function keys for high-frequency commands?	O	O	X	
8.7	For data entry screens with many fields or in which source documents may be incomplete, can users save a partially filled screen?	O	O	X	
8.8	Does the system automatically enter leading zeros?	O	O	X	
8.9	If menu lists are short (seven items or fewer), can users select an item by moving the cursor?	O	O	X	
8.10	If the system uses a type-ahead strategy, do the menu items have mnemonic codes?	O	O	X	
8.11	If the system uses a pointing device, do users have the option of either clicking on fields or using a keyboard shortcut?	O	O	X	
8.12	Does the system offer "find next" and "find previous" shortcuts for database searches?	O	O	X	
8.13	On data entry screens, do users have the option of either clicking directly on a field or using a keyboard shortcut?	O	O	X	
8.14	On menus, do users have the option of either clicking directly on a menu item or using a keyboard shortcut?	O	O	X	
8.15	In dialog boxes, do users have the option of either clicking directly on a dialog box option or using a keyboard shortcut?	O	O	X	
8.16	Can expert users bypass nested dialog boxes with either type-ahead, user-defined macros, or keyboard shortcuts?	O	O	X	


9. Aesthetic and Minimalist Design

Dialogues should not contain information which is irrelevant or rarely needed. Every extra unit of information in a dialogue competes with the relevant units of information and diminishes their relative visibility.

#	Review Checklist	Yes	No	N/A	Comments
9.1	Is only (and all) information essential to decision making displayed on the screen?	X	O	O	
9.2	Are all icons in a set visually and conceptually distinct?	X	O	O	
9.3	Have large objects, bold lines, and simple areas been used to distinguish icons?	X	O	O	
9.4	Does each icon stand out from its background?	X	O	O	
9.5	If the system uses a standard GUI interface where menu sequence has already been specified, do menus adhere to the specification whenever possible?	X	O	O	
9.6	Are meaningful groups of items separated by white space?	O	X	O	
	Increase use of white				
9.7	Does each data entry screen have a short, simple, clear, distinctive title?	X	O	O	
9.8	Are field labels brief, familiar, and descriptive?	O	O	X	
9.9	Are prompts expressed in the affirmative, and do they use the active voice?	X	O	O	
9.10	Is each lower-level menu choice associated with only one higher level menu?	O	O	X	
9.11	Are menu titles brief, yet long enough to communicate?	X	O	O	
9.12	Are there pop-up or pull-down menus within data entry fields that have many, but well-defined, entry options?	O	O	X	

10. Help and Documentation

Even though it is better if the system can be used without documentation, it may be necessary to provide help and documentation. Any such information should be easy to search, focused on the user's task, list concrete steps to be carried out, and not be too large.

#	Review Checklist	Yes	No	N/A	Comments
10.1	If users are working from hard copy, are the parts of the hard copy that go on-line marked?	X	O	O	
10.2	Are on-line instructions visually distinct?	X	O	O	
10.3	Do the instructions follow the sequence of user actions?	X	O	O	
10.4	If menu choices are ambiguous, does the system provide additional explanatory information when an item is selected?	O	X	O	
10.5	Are data entry screens and dialog boxes supported by navigation and completion instructions?	X	O	O	
	 <p>The instructions are more confusing than helpful as background does not separate them in anyway. A vidoe may be more helpful.</p>				
10.6	If menu items are ambiguous, does the system provide additional explanatory information when an item is selected?	O	X	O	
10.7	Are there memory aids for commands, either through on-line quick reference or prompting?	O	O	X	
10.8	Is the help function visible; for example, a key labeled HELP or a special menu?	O	X	O	
10.9	Is the help system interface (navigation, presentation, and conversation) consistent with the navigation, presentation, and conversation interfaces of the application it supports?	O	O	X	
10.10	Navigation: Is information easy to find?	O	X	O	

10.11	Presentation: Is the visual layout well designed?	O	X	O	
10.12	Conversation: Is the information accurate, complete, and understandable?	O	X	O	
	Some misleading and confusing information and 'lost' pages.				
10.13	Is the information relevant?	X	O	O	
10.14	Goal-oriented (What can I do with this program?)	O	X	O	
10.15	Descriptive (What is this thing for?)	O	X	O	
10.16	Procedural (How do I do this task?)	O	X	O	
10.17	Interpretive (Why did that happen?)	O	X	O	
10.18	Navigational (Where am I?)	O	X	O	
	Refer to Cognitive Walkthrough report				
10.19	Is there context-sensitive help?	O	X	O	
10.20	Can the user change the level of detail available?	O	X	O	
10.21	Can users easily switch between help and their work?	O	O	X	
10.22	Is it easy to access and return from the help system?	O	O	X	
10.23	Can users resume work where they left off after accessing help?	O	X	O	

11. Skills

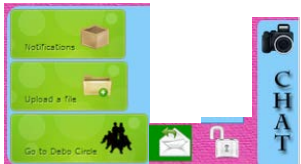
The system should support, extend, supplement, or enhance the user's skills, background knowledge, and expertise ----not replace them.

#	Review Checklist	Yes	No	N/A	Comments
11.1	Can users choose between iconic and text display of information?	O	X	O	
11.2	Are window operations easy to learn and use?	O	X	O	
11.3	If users are experts, usage is frequent, or the system has a slow response time, are there fewer screens (more information per screen)?	O	O	X	
11.4	If users are novices, usage is infrequent, or the system has a fast response time, are there more screens (less information per screen)?	O	O	X	
11.5	Does the system automatically color-code items, with little or no user effort?	X	O	O	
11.6	If the system supports both novice and expert users, are multiple levels of detail available.	O	O	X	
11.7	Are users the initiators of actions rather than the responders?	O	O	X	
11.8	Does the system perform data translations for users?	O	O	X	
11.9	Do field values avoid mixing alpha and numeric characters whenever possible?	O	O	X	
11.10	If the system has deep (multilevel) menus, do users have the option of typing ahead?	O	O	X	
11.12	When the user enters a screen or dialog box, is the cursor already positioned in the field users are most likely to need?	O	O	X	
11.13	Can users move forward and backward within a field?	O	O	X	
11.14	Is the method for moving the cursor to the next or previous field both simple and visible?	O	O	X	
11.15	Has auto-tabbing been avoided except when fields have fixed lengths or users are experienced?	O	O	X	
11.16	Do the selected input device(s) match user capabilities?	O	O	X	
11.17	Are cursor keys arranged in either an inverted T (best for experts) or a cross configuration (best for novices)?	O	O	X	

#	Review Checklist	Yes	No	N/A	Comments
11.18	Are important keys (for example, <u>ENTER</u> , <u>TAB</u>) larger than other keys?	O	O	X	
11.19	Are there enough function keys to support functionality, but not so many that scanning and finding are difficult?	O	O	X	
11.20	Are function keys reserved for generic, high-frequency, important functions?	O	O	X	
11.21	Are function key assignments consistent across screens, subsystems, and related products?	O	O	X	
11.22	Does the system correctly anticipate and prompt for the user's probable next activity?	O	O	X	

12. Pleasurable and Respectful Interaction with the User

The user's interactions with the system should enhance the quality of her or his work-life. The user should be treated with respect. The design should be aesthetically pleasing- with artistic as well as functional value.

#	Review Checklist	Yes	No	N/A	Comments
12.1	Is each individual icon a harmonious member of a family of icons?	O	X	O	
	 <p>They are not part of a single family of icons</p>				
12.2	Has excessive detail in icon design been avoided?	O	X	O	
	The two black icons don't have much detail, the others do.				
12.3	Has color been used with discretion?	O	X	O	
	Can use more white as text background				
12.4	Has the amount of required window housekeeping been kept to a minimum?	X	O	O	
12.5	If users are working from hard copy, does the screen layout match the paper form?	O	O	X	
12.6	Has color been used specifically to draw attention, communicate organization, indicate status changes, and establish relationships?	O	X	O	
12.7	Can users turn off automatic color coding if necessary?	O	X	O	
	Accessible colour theme options would be good.				
12.8	Are typing requirements minimal for question and answer interfaces?	X	O	O	
12.9	Do the selected input device(s) match environmental constraints?	X	O	O	
12.13	If the system uses multiple input devices, has hand and eye movement between input devices been minimized?	O	O	X	
12.14	If the system supports graphical tasks, has an alternative pointing device been provided?	O	O	X	
12.15	Is the numeric keypad located to the right of the alpha key area?	O	O	X	

12.16	Are the most frequently used function keys in the most accessible positions?	O	O	O	
	This will be evident once the site has been used for a while.				
12.17	Does the system complete unambiguous partial input on a data entry field?	X	O	O	

13. Privacy

The system should help the user to protect personal or private information- belonging to the user or the his/her clients.

#	Review Checklist	Yes	No	N/A	Comments
13.1	Are protected areas completely inaccessible?	X	O	O	
13.2	Can protected or confidential areas be accessed with certain passwords.	O	O	O	
	Security is in 3 layers: <ul style="list-style-type: none">• Unless logged in, no information is accessible.• Once logged in, all uploaded information is available.• Care Circle specific information is available only if you are member				
13.3	Is this feature effective and successful.	X	O	O	
	Desirable feature would be complete control for legal carer to control access of each Care Circle member.				

Heuristic Evaluation

A System Checklist

Primary Source

Making Computers-People Literate. © Copyright 1993.

By

Elaine Weiss

ISBN: 0-471-01877-5

System Title: _____

Release #: _____

Evaluator: _____

Date: _____

Secondary Source

Usability Inspection Methods. © Copyright 1994.

By

Jakob Nielsen and Robert Mack

ISBN: 1-55542-622-0

Xerox
The Document Company

Evaluation Plan

The redesign of version 2 of mycarecircle.com in Chapter 8 was ready to be opened to participants from the general public. However, an empty or unpopulated social network cannot be used. Therefore, the decision was made to carry out co-design and populate the site information.

Ethical had been obtained previously for user testing. This approval had to be extended to cover co-design and opening the website to complete Care Circles.

Step 1: Co-design design session with Dr. Mary Akinola from NHS

A demo of my Care Circle was done for Dr Akinola who was a participant and evaluator of the first version of the site. She has request for an introduction, physical conditions, of potential participants and potential environments of participants to help identify support material.

Dr Akinola will collect information from NHS that help meet task demands in the following areas:

The platform will be pre-populated with:

- Assessments
- Assistive Technology
- Care and Hygiene
- Education
- Entertainment
- Funding Assistance
- Psychological Needs
- Support for Carers
- Therapy
- Technical Support for AT

Once there is sufficient information in the platform to address at least three different types of physical conditions.

Step 2: Participant Recruitment

Participants will be from personal contacts, including those who contributed to earlier questionnaire and those professionally recommended by Dr. Mary Akinola.

The process of usage will be as follows and this will involve:

- Registration of user
- Creating a Care Circle per disabled individual
 - Adding details of profile such as description of special needs, AT devices, environments where support is required.
 - Invite Family members, medical professionals, educators or other

parents or carers of similar individuals or whomever you think fit to be members.

Step 3: Active usage

Using this web platform, you can:

- Effective communication via private messages, restricted and public forums and video chats
- Provide continuous support thereby reducing expensive assessment
- Create and keep track of events
- Share information

For two months, a fortnightly guide with tasks will be provided to each care circle to encourage usage. With the Care Circle's permission, I will also be a member of the circle.

Step 4: Results

As I am also introducing the tasks and being an active participant, there will be bias. However, without a pre-populated platform or the introduction of tasks, there may be no usage.

Being part of the Care Circles will enable me to conduct observations of:

- engagement frequency;
- nature of engagement;

To identify the impact of this bias, a survey will be conducted at the end of the study. Survey will be conducted with the participants of the study and will measure:

- efficiency of care circle engagement;
- effectiveness of care circle engagement;
- improvements in child's personal social and environmental factors;
- appropriate and timely support by more members of care circle;
- improved communication;
- better informed life style support;
- don't feel isolated;
- better, flexible AT support
- more frequent and accurate assessments
- reliable and important information ready to hand and accessible
- availability of impromptu tips and tricks from peers for child's lifestyle
- more appropriate and timely support by more members of care circle
- reduced breakdown in communication between school and parents as child struggles to communicate

- reduce waste time repeating information and miss out on receiving possible useful information

Data from the message content will be used to:

- identify purpose of communication;
- engagement;
- problem solving

Google analytics will be used to identify:

- the type of device used to access the website, whether mobile or fixed;
- location from where the website is accessed;

Online data will be stored for as long as the website is active. Participants have rights to remove data or close their account at any time after signing up.

The developer has administrator access for development of the website and data. I have an administrator access to verify details of registered users. However, I cannot join or participate in a care circle without the authorisation of the legal guardian.

There is a 12 month maintenance agreement between myself and the developer. The Developer will only access personal data if participants report a technical problem to me.

While the online data will remain in a secure server for as long as the website is live or the user chooses to close the account, other digital notes or copies made to evaluate the data will be kept in a password protected personal laptop until the end of the PhD and any relevant publications and thereafter destroyed.

Step 5: Evaluation

The worthwhile outcomes and Adverse Outcome identified in the worth sketch would be used to measure costs and benefits of the study. The relevant instruments of measurement are listed against them.

Worthwhile outcomes	Instrument of measurement	Adverse Outcomes	Instrument of measurement
a) More frequent engagement of more care circle members	<ul style="list-style-type: none"> • Record of communication • Observation • Compare with questionnaire 	a) Few care circle members frequently participate	<ul style="list-style-type: none"> • Record of communication • Observation • Compare with questionnaire

	data		data
b) More rapid improvements child's personal social and environmental factors	<ul style="list-style-type: none"> Survey (parents and professionals) 	b) Lack of impromptu tips and tricks from peers for child's lifestyle	<ul style="list-style-type: none"> Observation
c) More appropriate and timely support by more members of care circle	<ul style="list-style-type: none"> Survey (parents and professionals) 	c) More appropriate and timely support by more members of care circle	<ul style="list-style-type: none"> Survey (parents and professionals)
d) Improved communication	<ul style="list-style-type: none"> Survey (parents and professionals) 	d) Breakdown in communication between school and parents as child struggles to communicate	<ul style="list-style-type: none"> Survey (parents and professionals)
e) Better informed life style support	<ul style="list-style-type: none"> Survey (parents) 	e) Waste time repeating information and miss out on receiving possible useful information	<ul style="list-style-type: none"> Survey (professionals)
f) Don't feel isolated	<ul style="list-style-type: none"> Survey (parents) 	f) Feel singled out and just another child (instead of unique and special)	<ul style="list-style-type: none"> Survey (parents)
g) Better, flexible AT support	<ul style="list-style-type: none"> Survey (parents and professionals) 	g) Little and even no technical support for AT devices	<ul style="list-style-type: none"> Survey (parents and professionals)
h) More frequent and accurate assessments	<ul style="list-style-type: none"> Record of communication Compare with questionnaire data 	h) Assessments are bi-annually or annually: children grow fast	<ul style="list-style-type: none"> Record of communication Compare with questionnaire data
i) Reliable information	<ul style="list-style-type: none"> Survey (parents) 	j) Difficult to identify reliable	<ul style="list-style-type: none"> Survey (parents)

ready to hand		sources and readily available information	
k) Important documents and forms ready to hand	<ul style="list-style-type: none"> Survey (parents) 	m) Only hardcopies available from specific sources by special permission	<ul style="list-style-type: none"> Survey (parents)
n) Shared specific information is independently accessible	<ul style="list-style-type: none"> Survey (parents) 		

Further, any worthwhile and/or adverse experiences that are not addressed in the worthwhile/adverse outcomes will also be recorded.

Worthwhile experience	Instrument of measurement
a) Manageable schedules	
b) Dependable knowledgebase	
c) Satisfactory service	
d) Confident communication	
e) Reduced stress	
f) Motivated	
g) Moral support	
h) Reduce time and travel demands	
i) Empathetic environment	
j) Convenient	

Adverse Experience	Instrument of measurement
a) Fewer decision makers	
b) Support and advice delay	
c) Assessments only annual	
d) Poor professionals family communication	
e) Too many methods of communication	
f) Feel isolated	
g) Insufficient tech support	
h) Poor off-site support	
i) Inconsistent, unreliable or no information	
j) Inflexible solutions	

This data will be used to revise the worth sketch and conclude the study.

CARE CIRCLES - FEEDBACK

The idea of the Care Circle is as it sounds; believable and an innovative. Obviously a great deal of thought has gone into this with the theory of improving the capability of young children with motor impairment along with this their quality of life.

The following points I would like to mention:-

- The development of the online system to improve social networking – would assist with the difficulty of travelling long distances which of course could create issues for those with motor impairment?
- The online system could assist in areas of the country which are more remote and those areas that become more difficult to access owing to bad weather conditions?
- The online system could be helpful to young children who frequently attend medical appointments ie. Physio or their medication may influence the timings on outings to friends?
- The word 'support' is a useful term! How to cope, how to suggest coping skills and ideas for others and just the word 'sharing' and communicating with others with similar difficulties – REALLY HELPS.
- This online system could help to extend friendships and share interests for individuals whose capability may be seen as 'not so good', thus encouraging and promoting good self-esteem and even enhancing one's mood and mental well-being – (important in children.)
- Learning ability and skill-building is very important and those who may miss lessons at school through no fault of their own have every right to have a chance to better themselves and not drop behind owing to their personal disability?
- It is not unusual for disabilities such as motor impairment to create isolation and help or assistance from an online system could help with one's acceptance of the disability they have?
- The online system could also be seen as a 'recovery promoter' after hospitalisation or feeling generally low?
- Also a stimuli and an activity when family/carers are busy around the home?
- It could be difficult for some families/carers to access this online system owing to personal funding difficulties?
- CONFIDENTIALITY! - This must be seen as paramount. Many Professionals may not be keen to share tasks at all; codes of conduct they follow and ethical guidelines?
- Families/carers themselves may not be happy to share such personal information, especially if they are had bad experiences in the past?
- Family members may too embarrassed by asking questions about other members in their own family? It would not be helpful to exacerbate issues that exist already?
- Could this be seen only as a Research Project and not beneficial therefore to 'realistic situations?' The use being for scientific data value only?
- A face-to-face meeting I do continue to believe is the best way of communicating if possible! The personal character, warmth of one child meeting another, even if they have disabilities

is amazing in itself! The actual bond appears to be so great – so important and so gratifying to see for families and their carers.....

NB:- Sharing information is good practice in some instances. However, sharing in the hands of Those who think they are aiding an individual by suggesting a type of therapy or new activity can often cause more harm than a positive outcome? Careful consideration and examining the wider field as you are doing cannot be emphasised enough.

Good Luck with your Study.

Jacqui Bourton

C9 - School 2

School 2 is a school for children with behavioural problem. Majority of these students have diagnosed conditions such as Autism, Aspergers, ADHD, ADD and other learning disabilities such as Dyslexia and Dyspraxia.

10.30 Arrive, quick chat with JJ (deputy head teacher) and tour of the school.

During this time, I received an overview of the school. Most of the children have been excluded at least twice from other mainstream school on the basis of violent incidents. There are 71 boys and 5 girls in the school in years 1-5. There are 8 students in each class. Due to the nature of the special need there is physical force used by permission to control children. There is also a 'time out' room that is used for behaviour management where a child can be taken to help manage their emotions without hurting themselves or others. One of the causes for behavioural problem is reported as undiagnosed or delayed diagnosis of disabilities. Children here are supported for special needs and behavioural problems.

10.45 Mr S's Class (Years 5 and 6).

They were just completing some handwriting work as I was joined the class. The classroom had 8 boys aged 9-11. In addition to Mr S, there is a teaching assistant in the class. Students had their names written on the back of the chairs.

One child was asked to clear breakfast. Another child was asked to check if the Art room was ready for them to go in. As there was a delay in this, Mr S decided to take the class to play football. When children refused to take instructions, it was explained why they needed to be respected and how they had earned the right to it. Students were also taught how to appreciate things. Team work was actively encouraged from simply practices such as not commenting on team mates weak performances or mistakes, not arguing and encouraging each other.

After the game, cleaning washing and tidying was also checked.

They returned to their class to learn how to improve structure of sentences. They were corrected when they interrupted each other and taught to be respectful. They were also corrected for trying to seek attention or show off. Some children were allowed to get the help of thesaurus or dictionary while others were not. This was a decision made based entirely on special needs. The class left for their Art lesson in a different building. I left to the next class.

11.30 Mrs Gs' Class (Years 3 and 4)

Children were learning handwriting. There was soft background music and the students were very quiet. They moved on to read. There was one child who signed where I could get sweets from. I refused to take. He then went and asked permission from the teacher if he could read to me. Once permission was granted he read from his favourite story book and after that I wrote comments on his homework book. The boy thanked me and said he'd like to read to me again sometime. Thereafter we left for lunch.

In the background: there are children who refuse to read and those who cannot read due to specific learning difficulties. Some of them are supported while there was one student who was read to.

12.0 Lunch in the hall.

I joined the JJ and her table for the meal with 6 children and one teacher/teaching assistant. Once again, this was a time where children were trained. There was one children responsible for serving and tidying. They are taught how to sit and wait for the meal; to use cutlery and have quiet meals. JJ mentioned that normally children with conditions such as ADHD are assigned duties as they get find it difficult if they finish their meals quickly. The boy next to me was ADD and helped with bringing water and dessert once others finished their meal. He also asked me how long I was going to be in the school and what I did when I was not there. The school recites different religious prayers each day of the week both before and after the meal. Following the meal, I left with Mrs P to her class.

12.30 Mrs P's Class (Years 1 and 2).

There was one girl and seven boys in the class. The children had to start with reading. There was one boy who introduced himself to me. He couldn't read so he brought books for me to look at. There were two other boys who read to me. This was followed by handwriting. After they practised for a while, I left the classroom. There was a boy who interrupted the class to take something the class had borrowed from his. I left at the same time. He asked if I knew where I was going and offered to show me the way.

1.0 Coffee break in the staff room

I waited for JJ to arrive and then we went to her office.

1.15 Meet with JJ to demonstrate tool and gather feedback.

I couldn't understand how such well behaved children could be classified as those with behavioural problems. JJ informed me that all of the children had been excluded from main stream schools at least twice and 80% of them have broken their teachers limbs or nose. JJ added that the behaviour was a result of poor parenting, frustrations due to undiagnosed or misdiagnosed disabilities or a combination of this. Once the children had good discipline guidance and support for their needs including emotion management, they were much better. The children also liked to know that they were not the only bad people in the world.

The biggest challenge for the school particularly for children with complex needs is that they don't get similar guidance at home and the parents are not aware of how to bring up their children.

JJ spends a lot of time sending emails, letters and over the phone talking to parents.

I explained the rationale behind myCareCircle and did a demo. JJ was quite impressed. JJ didn't mind the aesthetics, she said she quite liked it. Her view was that this would centralise the information and reduce the time spent on repeating information to parents. It would also make the communication between social workers involved a lot easier. She recommended having some sort of 'alert' system

would be helpful. The website will be more helpful to children who have complex needs compared to those who have improved as a disability had been identified and supported. I also learnt that the government policy on inclusive education is being withdrawn and children have access to special needs schools.

Finally she mentioned that it will be great to extend this to social services to manage cases.

They would like to use myCareCircle once the website has been updated to see if they could use it on a regular basis for children with complex needs.

C9 - Screen Designs



Home > Brogan

Jennifer George is Logged in | [Log out](#)

my care circle

Care Circle Memberships

I am Brogan's Aunt

I am Dina's mother

Create Care Circle

Upload a photo of the person you care for

Choose file

Full Name

Date of Birth 1 Jan 2011

I am the Select relationship

Save

Invite to join your Care Circle

Search by Name

Search by Circle

Tell others about this website

Type friend's email here

Send Invite

Brogan Thomas

Care Circle Members

Questions and Answers

Share files

The number of members in Dina's Care Circle is: 3

Jennifer George

Aunt

Message

Remove

Tom Jones

Teacher

Message

Remove

Lucy Smith

Speech Therapist

Message

Remove

Carer's Profile

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About My Care Circle Project

Privacy

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1

Home > Brogan

Jennifer George is Logged in | [Log out](#)

Brogan Thomas

Care Circle Members

Questions and Answers

Share files

Care Circle Memberships

I am Brogan's Aunt

I am Dina's mother

Create Care Circle

Upload a photo of the person you care for

Full Name
 Date of Birth
 I am the

Invite to join your Care Circle

Tell others about this website

Type friend's email here

Carer's Profile

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Home > Brogan

Jennifer George is Logged in | [Log out](#)

Care Circle Memberships

You have not created or joined any care circles yet.

Create Care Circle

Upload a photo of the person you care for

Full Name
 Date of Birth
 I am the

Invite to join your Care Circle

Tell others about this website

Type friend's email here

Select or create a care circle to view and edit information.

Carer's Profile

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my care circle

MyCareCircle is a free social network dedicated to support individuals with disabilities.

If you are the main carer of an individual with disability, you may:

- Register yourself
- Create a CareCircle per disabled individual
- Invite family members, medical professionals, educators or other parents or carers of similar individuals or whomever you think fit to be members.

This will create a community made of many CareCircles that will continuously support the development of individuals with special needs.

Already Registered?

Email

Password

[Forgot your password?](#)

[Log in](#)

Want to Register?

Full Name

Email

Password

Re-type Password

[Help?](#)

[Register](#)

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Home > Brogan

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my care circle

Brogan Thomas

Care Circle Members

Questions and Answers

Share files

Care Circle Memberships

I am Brogan's Aunt

Create Care Circle



Upload a photo of the person you care for

[Choose file](#)

Full Name

Date of Birth 1 Jan 2011

I am the Select relationship

[Save](#)

Invite to join your Care Circle

[Search by Name](#)

[Search by Circle](#)

Tell others about this website

Type friend's email here

[Send Invite](#)



You have successfully joined Brogan's Care Circle

[OK](#)

Carer's Profile

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Home > Web invite confirmation

Jennifer George is Logged in | Log out

Care Circle Memberships

I am Brogan's Aunt

I am Dina's mother

Create Care Circle

Upload a photo of the person you care for

Choose file

Full Name

Date of Birth

1

▼

Jan

▼

2011

▼

I am the

Select relationship

▼

Save

Invite to join your Care Circle

Search by Name

Search by Circle

Tell others about this website

Type friend's email here

Send Invite

Select or create a care circle to view and edit information.

An email has been sent telling your friend about this website.

OK

Carer's Profile

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About My Care Circle Project

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Home > Web invite confirmation

Jennifer George is Logged in | Log out

Care Circle Memberships

I am Brogan's Aunt

Create Care Circle

Upload a photo of the person you care for

Choose file

Full Name

Date of Birth

1

▼

Jan

▼

2011

▼

I am the

Select relationship

▼

Save

Invite to join your Care Circle

Search by Name

Search by Circle

Tell others about this website

Type friend's email here

Send Invite

You are invited by Tracy Williams to join Tom's care circle.

Accept and join

Ignore

You are invited by Tom Jones to join Tracy's care circle.

Accept and join

Ignore

Carer's Profile

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Home > Notification > Ignore

Jennifer George is Logged in | [Log out](#)

Care Circle Memberships

I am Brogan's Aunt
I am Tracy's Teacher

Create Care Circle

Upload a photo of the person you care for

Full Name
Date of Birth 1 Jan 2011
I am the Select relationship

Invite to join your Care Circle

Tell others about this website

Type friend's email here

You have ignored an invite to join a care circle. The invitee will not be notified of this.
If you change your mind, search by name and accept.

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Home > Notification > Successful

Jennifer George is Logged in | [Log out](#)

Care Circle Memberships

I am Brogan's Aunt
I am Tracy's Teacher

Create Care Circle

Upload a photo of the person you care for

Full Name
Date of Birth 1 Jan 2011
I am the Select relationship

Invite to join your Care Circle

Tell others about this website

Type friend's email here

You have successfully joined a care circle. A confirmation has been sent to the invitee.

You are invited by Tom Jones to join Tracy's care circle.

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Jennifer George is Logged in | [Log out](#)

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[Care Circle Members](#)
[Questions and Answers](#)
[Share files](#)

Care Circle Memberships

I am Brogan's Aunt

Create Care Circle

Upload a photo of the person you care for

Full Name
 Date of Birth 1 Jan 2011
 I am the Select relationship

Invite to join your Care Circle

Search by Name
 Search by Circle

Tell others about this website

Type friend's email here

Ask Questions

+

Past Questions and Answers

-

Any recommendations for a toy to learn KS1 numeracy? 2 months ago by Jennifer George

Board Maker, Blah Blah, etc. 2 days ago by Eddy Ferreira

Any recommendations for a toy to learn KS1 numeracy? 2 months ago by Jennifer George

Board Maker, Blah Blah, etc. 2 days ago by Eddy Ferreira

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[Care Circle Members](#)
[Questions and Answers](#)
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Care Circle Memberships

I am Brogan's Aunt

Create Care Circle

Upload a photo of the person you care for

Full Name
 Date of Birth 1 Jan 2011
 I am the Select relationship

Invite to join your Care Circle

Search by Name
 Search by Circle

Tell others about this website

Type friend's email here

Ask Questions

-

Type your question here

Past Questions and Answers

+

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6

Home > Carer

Jennifer George is Logged in
Log out

Care Circle Memberships

I am Brogan's Aunt

I am Dina's mother

Create Care Circle

Upload a photo of the person you care for
Choose file

Full Name

Date of Birth
1
Jan
2011

I am the
Select relationship

Save

Invite to join your Care Circle

Search by Name

Search by Circle

Tell others about this website

Type friend's email here

Send Invite

Jennifer George

Upload a photo of yourself
Choose file

Email
jenni26cg@gmail.com

Phone
123 4567 8901

Skype
abs_defg

Other details

Edit Details

Carer's Profile

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Jennifer George is Logged in
Log out

Brogan Thomas
Care Circle Members
Questions and Answers
Share files

Care Circle Memberships

I am Brogan's Aunt

Create Care Circle

Upload a photo of the person you care for
Choose file

Full Name

Date of Birth
1
Jan
2011

I am the
Select relationship

Save

Invite to join your Care Circle

Search by Name

Search by Circle

Tell others about this website

Type friend's email here

Send Invite

Ask Questions
+

Past Questions and Answers
+

You have successfully responded to a Question.
OK

Carer's Profile

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my care circle

Home > Registration Confirmation

Step 2 of 2



You have successfully registered.
Check your email and follow instructions to log in.

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Home > Search

Jennifer George is Logged in | [Log out](#)

Care Circle Memberships

I am Brogan's Aunt

I am Dina's mother

Create Care Circle



Upload a photo of the person you care for
[Choose file](#)

Full Name

Date of Birth 1 Jan 2011

I am the Select relationship

[Save](#)

Invite to join your Care Circle

[Search by Name](#)

[Search by Circle](#)

Tell others about this website

Type friend's email here

[Send Invite](#)

Search Results for Circles....



[Send Message](#)

Full Name **Sam Grisham**
Carer's Email **grishams@gmail.com**
Father of Sam

[Request to join circle](#)



[Send Message](#)

Full Name **Miko Bosco**
Carer's Email **boscos@bosco.com**
Father of Miko

[Withdraw request to join circle](#)



[Send Message](#)

Full Name **Sam Grisham**
Carer's Email **grishams@gmail.com**
Father of Sam

[Request to join circle](#)



[Send Message](#)

Full Name **Sam Grisham**
Carer's Email **grishams@gmail.com**
Father of Sam

[Request to join circle](#)

Carer's Profile

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my care circle

Home > Registration Help

Step 1

Want to Register?

Full Name	<input type="text"/>	Please enter full name for security reasons and this is the name by which others would recognise you
Email	<input type="text"/>	Please enter the email that you access regularly. e.g. johnsmith@something.com
Password	<input type="password"/>	Please type a password you will remember, is secure and approximately 6 characters.
Re-type Password	<input type="password"/>	Please re-type the password
<input type="button" value="Register"/>		

Step 2

If you entered your details correctly, you will see the following message upon pressing the 'Register' button.



You have successfully registered.
Check your email and follow instructions to log in.

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Home > Search

Jennifer George is Logged in |

my care circle

Care Circle Memberships

I am Brogan's Aunt

I am Dina's mother

Create Care Circle

Upload a photo of the person you care for

Full Name

Date of Birth 1 Jan 2011

I am the Select relationship

Invite to join your Care Circle

Tell others about this website

Type friend's email here

Search Results for Names...



Full Name Eddy Ferreira
Email mynameis@eddyf.co.uk
Therapist of Tom



Full Name Tracy Williams
Email mynameis@eddyf.co.uk
Sister of Jane



Full Name Eddy Ferreira
Email mynameis@eddyf.co.uk
Therapist of Tom



Full Name Eddy Ferreira
Email mynameis@eddyf.co.uk
Therapist of Tom

Carer's Profile

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Home > Search > Message confirmation

Jennifer George is Logged in | [Log out](#)

Care Circle Memberships

I am Brogan's Aunt

I am Dina's mother

Create Care Circle

Upload a photo of the person you care for

Full Name
Date of Birth 1 Jan 2011
I am the Select relationship

Invite to join your Care Circle

Tell others about this website

Type friend's email here

Search Results for Circles....

You have successfully sent a message.

Full Name Miko Bosco
Carer's Email boscos@bosco.com
Father of Miko

Full Name Sam Grisham
Carer's Email grishams@gmail.com
Father of Sam

Full Name Sam Grisham
Carer's Email grishams@gmail.com
Father of Sam

Carer's Profile

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Home > Search > Message Confirmation

Jennifer George is Logged in | [Log out](#)

Care Circle Memberships

I am Brogan's Aunt

I am Dina's mother

Create Care Circle

Upload a photo of the person you care for

Full Name
Date of Birth 1 Jan 2011
I am the Select relationship

Invite to join your Care Circle

Tell others about this website

Type friend's email here

Search Results for Names...

You have successfully sent a message.

Full Name Tracy Williams
Email mynameis@eddyf.co.uk
Sister of Jane

Full Name Eddy Ferreira
Email mynameis@eddyf.co.uk
Therapist of Tom

Full Name Eddy Ferreira
Email mynameis@eddyf.co.uk
Therapist of Tom

Carer's Profile

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Home > Brogan > Questions and Answers > Share Files

Jennifer George is Logged in | [Log out](#)

Brogan Thomas

Care Circle Members

Questions and Answers

Share files

Care Circle Memberships

I am Brogan's Aunt

Create Care Circle

Upload a photo of the person you care for

Full Name
Date of Birth 1 Jan 2011
I am the Select relationship

Invite to join your Care Circle

Tell others about this website

Type friend's email here

Select category from list

Assessments

Choose file

Share

Assistive technology

+

Care & Hygiene

+

Assessments

+

Education

+

Entertainment

+

Funding assistance

+

Psychological

+

Needs

+

Support for carers

+

Therapy

+

Technical support for assistive technologies

+

Carer's Profile

Notifications

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About My Care Circle Project

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Home > Brogan > Questions and Answers > Share Files > Successful

Jennifer George is Logged in | [Log out](#)

Brogan Thomas

Care Circle Members

Questions and Answers

Share files

Care Circle Memberships

I am Brogan's Aunt

Create Care Circle

Upload a photo of the person you care for

Full Name
Date of Birth 1 Jan 2011
I am the Select relationship

Invite to join your Care Circle

Tell others about this website

Type friend's email here

Select category from list

Assessments

Choose file

Share

Assistive technology

+

Care & Hygiene

+

Assessments

+

Education

+

Entertainment

+

Funding assistance

+

Psychological

+

Needs

+

Support for carers

+

Therapy

+

Technical support for assistive technologies

+

Carer's Profile

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You have successfully shared a file with all my care circle members.

About My Care Circle Project

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Home > Brogan > Questions and Answers > Past

Jennifer George is Logged in | [Log out](#)

Brogan Thomas

Care Circle Members

Questions and Answers

Share files

Care Circle Memberships

I am Brogan's Aunt

Create Care Circle

Upload a photo of the person you care for

Full Name
Date of Birth 1 Jan 2011
I am the Select relationship

Invite to join your Care Circle

Tell others about this website

Type friend's email here

Ask Questions

Past Questions and Answers

Any recommendations for a toy to learn KS1 numeracy? 2 months ago by Jennifer George

Board Maker, Blah Blah, etc. 2 days ago by Eddy Ferreira

Write or upload a response to the question:

Any recommendations for a toy to learn KS1 numeracy? 2 months ago by Jennifer George

Board Maker, Blah Blah, etc. 2 days ago by Eddy Ferreira

Carer's Profile

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	A	B	C	D	E	F	G	H	I	J	K	L	M
1		Jan-08	Feb-08	Mar-08	Apr-08	May-08	Jun-08	Jul-08	Aug-08	Sep-08	Oct-08	Nov-08	Dec-08
2	General		CiK: tests capability model for choice and use						CiK: tested WCD approaches for choice and use		Full formulation of the 3 RQs;		Beyond Bodies; Socio technical systems;
3	C1: Introduction												
4	C2: Contextual Review			AT survey for biomedical needs			ICF		biomedical approach; disability models;				
5	C3: Research Approach				Value Sensitive Approach vs. Skill of a Designer for successful AT; design for children;		WCD;	Adding MPs and considering systems approach	worth, meta-principles;	MSR Cycle			
6	C4: Activities 1-4	Activity 1-28th January 2008: The Centre Interviews (For Knowledge Elicitation Purpose (idea from DSS) to model disabilities); Activity 2 and 3: 29th January 2008: The School;				Assessment Methods; Focus on designing for Children; The Centre suggested working with SpeechBubble							
7	C5: Activities 5-8						Socio-Tech;					CAT model;	Proposal to the Centre on Speech Bubble
8	C6 - Activities 9-11												
9	C7- Activities 12-15												
10	C8: Activities 16-19												
11	C9: Activities 20-23												
12	C10: Conclusion												
13	Notes	Sunderland						Shareable: TableTops Paper					

	A	N	O	P	Q	R	S	T	U	V	W	X	Y
1		Jan-09	Feb-09	Mar-09	Apr-09	May-09	Jun-09	Jul-09	Aug-09	Sep-09	Oct-09	Nov-09	Dec-09
2	General						Slight amendments to RQs;			Idea for clan map (simple worth web); Document split to chapters		RQ3: changed and added RQ4	
3	C1: Introduction												
4	C2: Contextual Review							ICF model in detail for choice					
5	C3: Research Approach			MPs expanded;				Participatory Design;					
6	C4: Activities 1-4	Activity 4: Reflection on Personal Experience and Activity 5: STS started		Worth Map introduced; Locales;	Explored alternative models (sequential, flow, etc.)								
7	C5: Activities 5-8					End of Activity 5: New Socio-tech		Worth Web I; Activity 7: 21st July 2009 The Centre Interviews	Design Social network sketches	Built - Ning.com	Activity 6: JMH interview	Activity 8: CAT model (to assess accessibility)	
8	C6 - Activities 9-11						Questionnaires Design Started						
9	C7- Activities 12-15												
10	C8: Activities 16-19												
11	C9: Activities 20-23												
12	C10: Conclusion												
13	Notes				DSAI 2009 Paper: ICF	ICCHP Paper: CAT Model					Moved to Northumbria		

[illegible]

	A	BV	BW	BX	BY	BZ	CA	CB	CC
1		Jan-14	Feb-14	Mar-14	Apr-14	May-14	Jun-14	Jul-14	Aug-14
2	General								Revised all research questions and claims; Finished complete draft
3	C1: Introduction	Dropped Preface completely							
4	C2: Contextual Review								
5	C3: Research Approach							W2C framework added; completely dropped MPs	
6	C4: Activities 1-4								
7	C5: Activities 5-8								
8	C6 - Activities 9-11								
9	C7- Activities 12-15								
10	C8: Activities 16-19								
11	C9: Activities 20-23								
12	C10: Conclusion								
13	Notes								

Tabletop computers as Assistive technology, Jennifer George & Gilbert Cockton

{jennifer.george, gilbert.cockton}@sunderland.ac.uk

1. Introduction

This note explores the potential of tabletop computers as assistive technologies for young children between the ages of four and seven with severe physical impairment have been chosen. This group of children find competence in dexterity, coordination, speed of movement, hold-grasp capabilities challenging (Lindon, 1963) which may be due to laxity in muscles, tensed muscles, weak muscles, abnormal reflex activity, asymmetry, involuntary movements, growth factors and biomechanics (Levitt, 1995). These physical conditions may result in tremor, spasm, restricted range of motion and reduced strength (Keates, *et al.*, 2002). Most of them also use specialist chairs for controlled movement of arms and mobility, and gaining adequate control over computer-based devices can be an immense challenge.

2. Current AT for motor impaired children

Most assistive devices used by this group of children either work through a keyboard and mouse or emulate the functionality of the keyboard and mouse (WebAim, 2007). Alternative input modalities are introduced or existing devices are modified to cater to the special needs of users. Many ergonomic and assistive devices are also currently available in the market as both Augmentative and Alternative Communication (AAC) which can be used to add to the more usual methods of speech, writing and Assistive Technology (AT) to enable independence for individuals with special needs. Communication devices can be categorised as: *Low tech* — depend on no technology at the time it is being used; *Light tech* —need only limited technology to operate, e.g., a battery; and *High tech* —,based upon a greater degree of technology (Ace-Center, 2007).

ATs in education and at home

During the decision making process of selecting AT and AAC devices, in addition to assessing an individual's physical needs, their environment and care circle are also consulted (Ace, 2008). The care circle may include parents, teachers, SENCO, ICT coordinator, Advisory teacher, LSA/TA, educational psychologist, paediatrician, Speech and Language Therapist, Occupational Therapist and Physiotherapist. Parents are the only constant members of the care circle; other members can periodically change as the child develops cognitively and physically. Typically, children spend around six hours during term time during weekdays at school. The rest of the time spent at home with family and friends demand constant communication based activities. Any specific use of technology in school shouldn't be limited to school time. Parents, siblings and carers should also be competent in using the communication tools used by the child to communicate. Good selection and role-playing of AT devices encourage and motivate children to use them.

Most AT devices available for children in typical classroom computers use mice and keyboards as input devices. Mobile keyboards, alternative mice and monitor arms are some of the most prominent ones (SpecialNeeds Computer Solutions, 2007). Different types of adaptive keyboards are available, both virtual and physical. Most of AT and AAC devices are used by children with severe physical impairment while positioned on specialist chairs such as S.A.M seats, Convaaid Cruisers or Leckey Whoosh chairs while equipment is positioned on the tables fitted to their chairs or part of their environment. Constant use of arm, wrist and fingers are necessary to have complete control over computer-based systems. Special handles or grips may become necessary to hold small objects. Special bends, curves, handles and grips may also be necessary to improve motor skills (Zisook, 2007). When there is no control over the arm, alternative modalities such as muscle, speech, skin, eye pointer and head movements could also be used.

3. The Potential of Tabletop Computers

Media convergence can bring multiple technologies and devices together, combining their advantages. Ubiquitous or pervasive computing is brought about by the convergence of media and environment making interactivity more natural and less seamful. Touch and gestural interfaces such as Apple's iPod and iPhone, Microsoft Surface and Nintendo's Wii incorporate a variety of input, output, data, connectivity and interoperability.

Challenges of Tabletop interfaces

Surface, a tabletop interface, enables grabbing and moving data using natural touch and gestures (Microsoft, 2008). The direct interaction functionality requires no use of mouse or keyboard, which means more accurate hand movement will be required. The target group of children in this research are highly likely to have difficulty in making precise gestures or movements due to their limited control over fingers, hand, wrist and arms. A further challenge would be that their existing customised tabletop might not be within reach from their specialist seating positions, and also that they may not be able to seat at Tabletops with existing form factors, which tend to be more like kitchen islands in form than tables.

Potential for the user

ThinSight is a regular laptop based multi-touch interface that uses an optical sensing system placed behind an LCD (Izadi, *et al.*, 2007). This allows a much greater range of form factors than is possible with existing tabletop technologies. As Thinsight form factors become available, children in any seating position may become able to access tabletop interfaces.

The multi-touch contact enables many points of contact on screen, which means use of palm or fist in contrary to fingers could be used, rather than fingers. Object recognition on table top computers enables contact and connection with specialist low tech devices which are most used as communication devices at home. Tabletops offer a potential for integrating low tech and light tech devices into a more powerful high tech environment. Also, existing specialist mice, and keyboards may no longer be required, thus eliminating a need to counter errors relevant to mice and keyboards. Problems arising for the use of mouse and keyboards by users with special needs have been eliminated by the introduction self-adapting agents that can compensate for errors that are common among users with motor impairments (Trewin 2004, Trewin, *et al.*, 2006). Similar agents could augment existing tabletop system software to compensate for motor difficulties when interacting via low tech props (e.g., large pointing and selection objects with custom grips).

Potential for the care circle

The multi-user experience enables any member of the care circle to interact collaboratively without interrupting the user's control, thus creating further opportunities. This could lead to much more effective use of assistive technologies, and a corresponding acceleration in the educational development of the target group of users for our planned research. Different features could be provided to meet the needs of different roles within the care circle, as well as adapting table top assistive technologies for home, educational and therapeutic use.

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Towards Comprehensive ICF Compatible Sociodigital Approaches to Choice and Use of Assistive Technology for Young Children

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Abstract – The WHO has set demanding requirements for Assistive Technologies through its ICF, which existing approaches to assessment and design cannot fully meet. We use the ICF and a typical day at school for a child with severe motor impairment to review some existing approaches to assessment of children's special needs and to the design of Assistive Technologies to meet those needs. No approach reviewed can cover the broad range of considerations in the ICF. We therefore briefly review leading edge approaches to Interaction Design that may be able to meet the requirements for the worthwhile socio-digital systems implicit in the ICF.

I. INTRODUCTION

Many assessment methods are used to guide selection of communication and other aids for young children with motor impairment. For example, motor ability has been assessed by ambulation, manual dexterity, sensory ability in hearing and vision [1]. Simple scales of manual ability from 'normal' to 'unable to dress without assistance' have been used to assess group children with Cerebral Palsy, but they could also be used for more general physical capability limitations in children. Such assessments can guide the choice of Assistive Technologies (ATs), but essentially such biomedical approaches to assessment are narrow relative to current approaches to disability. For example, the International Classification of Functioning Disability and Health (ICF) is the framework used by the World Health Organisation (WHO). It models capability as the result of interactions between body function and structure, activities, participations of individuals and the contextual factors [2]. Contextual factors include the physical environment and personal values of the care circle of family and individuals encountered on a daily basis. Psychological and social factors must thus be considered, as an individual's environment disables them, and not merely bio-medical diagnoses of physical or other limitations.

This paper begins with at an ordinary day for a child, classified as 'disabled', to illustrate social settings and

the associated care circle. It next looks at some assessment methods used to select Assistive Devices, and then some models that have been developed to assist in choosing and using Assistive Devices. In both cases, assessment methods and models can rarely cover the full range of factors within the scope of the ICF. The paper closes by presenting current leading edge approaches from Human-Computer Interaction (HCI) that could move design, selection and use of AT beyond biomedical approaches to the full range of *biopsychosocial* considerations advocated in the ICF.

II. A TYPICAL DAY AT SCHOOL

A typical school day in a special school lasts from 9.00am to 3.00pm. The children start the day with a time of singing during which the children have to welcome each other and sing along. All teachers, teaching assistants (TA) and therapists are present for this session and help children carry out tasks. Non-verbal children would press buttons to indicate a hello and children with only eye movement would use eye gazer to select the relevant words. Actions for the songs are also introduced and encouraged and posture is continuously checked by the occupational therapist and the other helpers.

After singing time, children are grouped into two or three and sent for physical exercises guided by occupational therapists and class teachers where they exercise without any normal limb support. During this time the speech therapist also tries to get them to practice sounds while exercising. After their physical and speech training, they have drawing lessons where they develop fine motor control. Children who cannot draw with their hands use eye gaze or click buttons and switches to draw. After this, they have a break with drinks and go for a walk in the garden pushing a doll in a pushchair for support.

The children go for a swimming lesson with support workers and thereafter have lunch. All teachers and helpers try to make children independent by encouraging them to eat by themselves, but end up feeding most of them.

Following lunch, all children go for story time, while two by two they are called for speech therapy for about half an hour each. Where they are finding it hard to be understood, they learn to use an Assistive Device to support them. When all children complete their sessions, they have creativity time where children play with glue, paint, wool and material learning different textures while once again practicing their fine motor skills. Children are cleaned up after this messy session and they start playing with toys of their choice from making tea to computer based games.

Finally they are all called for a story time where they have to communicate using their own assistive devices to answer questions. They carry on playing while the parents come and collect them to go home.

The routine of the day would be the same for each day of the week, but have different stories, phonetics that go with them, games and drawing related to them, actions and supporting exercises making them real.

III. CARE CIRCLE AND COMMUNICATION

The roles covered in the above typical day (class teachers, speech therapists, occupational therapists, helpers) form a key part of a physically impaired child's *care circle*. A child with motor impairment above the age of 4 spends at least six hours per day and five days a week in school, making more than half of their day spent with family and friends. In a school environment, the child comes into day to day contact with teachers, helpers, therapists and other classmates. As children grow physically and cognitively, their teachers will change and their classmates may move to different main stream schools. They may have the same therapists for longer if the therapists also work independent of the schools. This leaves the members of the immediate and extended family as more permanent members of their care circle.

For example child T is 5 years old and suffers from Cerebral Palsy affecting all four limbs. She has very limited motor control over her arms and no control over her legs. Eye-gaze is her primary mode of communication and she looks at her right hand for yes and her left for a no. She is non verbal and can smile in approval. When she doesn't want to communicate she would just close her eyes. The regular contacts in the care circle are her parents, teacher, teaching assistant and peers at her school. She has no siblings or grandparents in regular contact. She is very intelligent and has a broad range of vocabulary which she uses with eye gaze, and at times via a head switch.

The responsibility of reducing the disability and increasing independence of a child depends greatly, not only on their therapists and teachers, but also on

their parents. Teachers and therapists aim to increase independence of children, but parents may not feel this independence as an important aim, and may accept and understand their child's special needs, helping by accomplishing tasks for them. Parents may also find it easier to perform the children's low-level life skill tasks for them, saving time and energy, especially amidst caring for other children of the family. They may also have to work. This special group of children need to be constantly encouraged to carry out low level tasks themselves with the challenges gradually increased.

Motor impaired children may need the support of low level or high level assistive devices to help them communicate and carry out day to day tasks. Although the low level tasks may be carried out for themselves, communication involves a second person who would be communicating with the child.

A child's care circle thus extends across their school, home and other social settings. A child may need to communicate with therapists, and in education and casual conversation. Fuller and colleagues thus argue that all care circle members must be considered as users when choosing and using AT devices [3]. They believe that each member of the care circle should be considered as an end-user, as they will use AT to communicate with children with motor impairment.

IV. TYPES OF ASSESSMENTS

A child's capability has to be assessed before suitable AT is selected for use. From the time of birth, all children are checked against a standard growth chart to check progress of physical, cognitive growth and language and fine motor skills development. If any delays or concerns arise, a UK child will be immediately referred to the community paediatrician who will carry out any further investigation to make referrals. Different institutions across a child's care circle may take different approaches to assessment.

A. UK National Health Service (NHS)

If the child is diagnosed at birth (or from the time a child is referred in the UK to the NHS by the community paediatrician), the child is referred to experts for intervention either in the form of therapy, medication or supported lifestyle. The NHS uses a general developmental chart to assess disorders. Community paediatricians carry out the developmental assessments based on growth charts and milestones [4]. The NHS uses a variety of assessments, some of which are explained below.

The NHS uses *Growing Skills* (second edition) aimed at 0-5 year olds [5]. This is a form-based assessment

completed by the Educational Psychologists, Special Educational Needs Coordinators (SENCO), Nursery Teachers, Paediatricians or Health Visitors. Some of the key areas covered in these assessments are: Passive Posture, Active Posture, Locomotor, Manipulative, Visual, Hearing and Language, Speech and Language, Interactive Social and Self-Care Social skills. The *Bruininks-Oseretsky Test of Motor Proficiency* (second edition) is used for 4-21 year olds and covers fine motor control, manual co-ordination, body co-ordination, strength and agility and a comprehensive measure of overall proficiency [6].

Movement Assessment Battery for Children (recently revised - Movement ABC - 2) is a UK standardised assessment tool examining manual dexterity, ball skills and balance. The Barley score, The Hammersmith motor ability score, Miller Assessment for pre-schoolers (MAP) are also used for assessments.

These assessments evaluate specific manual and cognitive skills. They do not take into account where the interaction would be situated, what purposes this would need to meet, or the influence of environment and personal factors.

B. Special Educational Need Coordinator Assessment

UK school teachers in a Special Educational Needs Coordinator (SENCO) role use *The Special Educational Needs* (SEN) five-question method to identify if a child is categorised as disabled under the UK's Disability Discrimination Act 2005. These questions look at motor and sensory skills related day-to-day activities, underlying impairment and conditions, if the condition or impairment would last for more than 12 months, and if it is more than minor or trivial [7]. Overall, this method appears to consider medical diagnoses and physical means to overcome the limitation.

C. The International Classification of Functioning Disability and Health

The ICF defines each of its *biopsychosocial* factors and breaks them down into various categories for functional status assessments, goal setting, treatment planning and monitoring and outcome measurement. The ICF has an associated checklist for clinicians as a practical tool to elicit and record information on functioning and disability of individuals. A general form covers all impairment both physical and cognitive spanning all ages. It is currently only in use in Australia, Italy and Netherlands, and is largely used to gather statistics and follow legislation[8]. Assessment includes impairment of body functions

and body structures, activity limitations and participation restriction, environmental factors, and other contextual information. In addition there is a health information form and participation and activity related questions that assist in deciding what in fact makes the individual disabled.

D. An Independent Organisation

In the UK, where the NHS is unable to meet the needs of the child successfully, the child can be referred to external organizations where further support can be provided. In one such independent communication evaluating organization, teams of 3-5 specialists spend 1/2 – 1 day to evaluate the needs of a child in order to recommend assistive devices, usage and therapy. Many assessment methods are used for evaluating alternative strategy needed and possible assistive device solutions. The centre also strongly believes that there is no 'general' way of assessing 'special' children [9][10].

Referrals are obtained from anyone who may be involved in the care circle including the teacher, SENCO, Information and Communication Technology coordinator,, Learning Support Assistant or Teaching Assistant, educational psychologist, paediatrician, Speech and Language Therapist, Occupational Therapists and physiotherapist. Background information is obtained from the parents or guardians with regard to the child's interests, sensory abilities, methods of communications used, reading and writing skills, seating and positioning, mobility, use of toys and control of environments, use of computers and any medical needs. In addition to similar information referrals also provide information on education together with relevant documents.

The assessment team primarily uses videos taken in familiar environments. During this time, seating and positioning, control of technology, use of computer and communication capabilities are assessed and an action plan put together considering educational, training and support issues.

It is important that sufficient knowledge of individuals is gained using task analysis and synthesis prior to formulating intervention plans. Task analysis will lead to fragmenting activities into physical and psychological components and synthesising to help to understand what the child enjoys, finds challenging or frustrating, which can lead to tool, environment and activity modifications. Some of the activities that can be used are Talking Mats™, Board Maker, Bubble Play, and Storytelling. Children with special needs get to see very few others using assistive devices and good role-modelling by the care circle motivates them to use them.

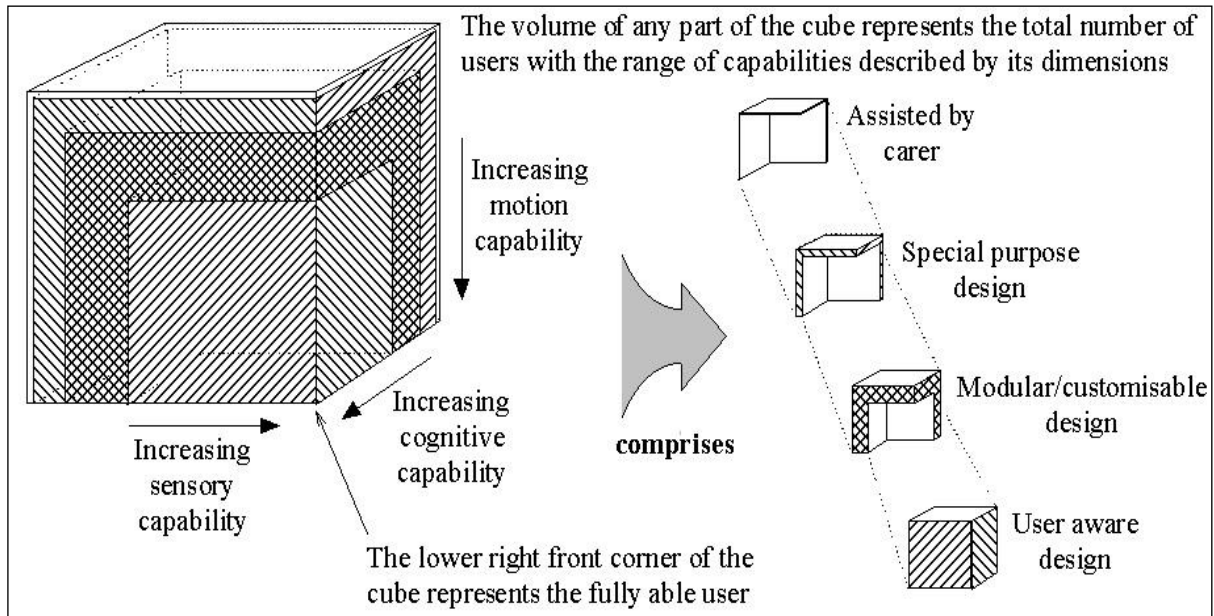


Figure 1 - Design Cube^[12]

A personal communication book is usually developed for each child and specific environmental control activities are also set up.

E. Summary

A child with major physical impairments may be assessed via a range of methods, depending on the factors that the assessing organisation believes to be important.

The UK NHS looks at the biological, medical and physical conditions that do not meet the requirements of the growth chart of a child. Neither the Growing Skills chart nor the Assessment Battery looks into the social or environmental factors that would possibly limit the child's ability to be less disabled. The SEN assessment looks at the class situation and whether the child needs any support to communicate within the set educational environment. Although consideration is given to a specific school social setting, members of the care circle within that setting, personal preferences or psychological factors that may affect the ability of the child are not considered, once again making this a biomedical approach with a single social consideration. The ICF is not an organisation that carries out assessment, but has developed an assessment based on biopsychosocial factors that has been made globally available. The independent organisation reviewed in this paper considers each possible environment of the child and each member of the care circle in addition to the medical diagnosis and physical limitations, and thus takes a broad biopsychosocial approach in contrast to other organisations.

V. REVIEW OF MODELS FOR CHOICE AND USAGE OF AT

Various models have been built to include motor impaired users by way of inclusive design. The choice of AT device needs to be suitable for both biomedical factors and fit within each social context, hence effective models need to have a sociodigital scope (see below) rather than just a biomedical one. This section reviews examples of models for use and choice of AT devices.

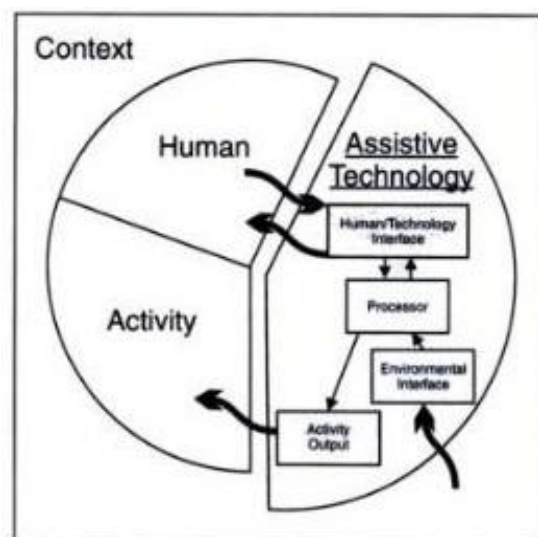


Figure 2 - HAAT model^[13]

Based on the wholly biomedical two-dimensional pyramid of Benktzon [11], the i-design research team developed a relatively advanced capability model [12].

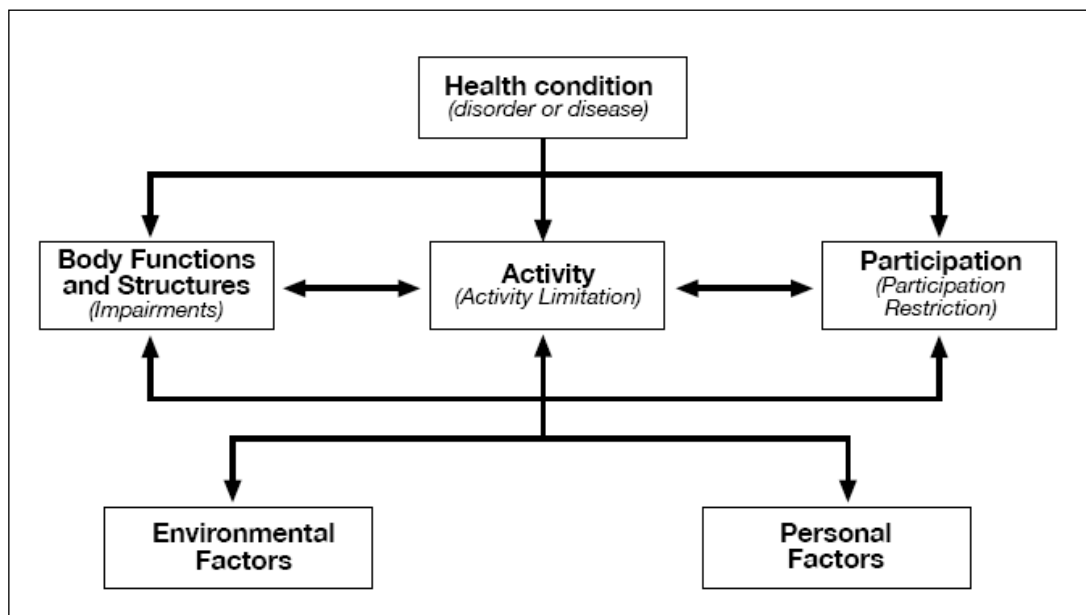


Figure 3 - ICF Framework ^[2]

This is a three-dimensional design cube that could guide the decision-making process for inclusive design (Figure 1) [12]. The design cube represents the whole population, where the bottom-front-right corner represents the fully capable user in terms of motion, cognition and sensory capabilities. The resulting design processes are categorised into user aware design, modular/customisable design, special purpose design and assisted by carer, where the position of users under consideration moves towards the back-top-left corner of the cube. Taking account of carers and assistant extends this model beyond a wholly biomedical one.

Cook and Hussey developed the Human Activity and Assistive Technology Model (HAAT) to indicate how human, AT and activity interact with each other in enabling achievement of goals, shaping the overall performance of an individual (Figure 2). Their 'human factors' refer to the skills available to meet the goals while their Context factor defines the constraints on goal achievement [13]. AT characteristics are defined by the goals, measured skills, and constraints of the context. Here the context depends on the definition of a specific activity and consideration of the human skills to achieve it. The HAAT model was the first to include non medical factors into the model. It uses the individual's biological capability *and their activities* to make choices or design, thus making a more fully biopsychological model than the i-cube. Models and frameworks developed by the Center for Research and Education on Aging and Technology Enhancement (CREATE) have a broader still biopsychological scope, based on human factors engineering and cognitive psychology [14]. Their frameworks are also dynamic, dealing with the changing capabilities of

older people thus, maximising the fit between the users and the technology by designing for the environment and ergonomic factors.

As already mentioned, the ICF framework is the most comprehensive, considering impairment of body functions and body structures, activity limitations and participation restriction, environmental factors, and other contextual information when defining disability (Figure 3). These additional attributes environmental and personal factors disable individuals, and not merely biomedical factors [2].

Models ranging from the Benktzon triangle to the ICF span biomedical to biopsychosocial approaches. While the i-cube considers the presence of a carer, both it and Benktzon's triangle fail to take into account the environmental and other factors that contribute towards the user's capability, especially child development and contextual factors. The HAAT model for the first time situates human, activity and AT within a set context and extends to a biopsychological model, but does not include social elements. CREATE gives more importance to environmental factors to obtain the best fit between AT and usage settings, but give less prominence to personal factors. Only the ICF has the breadth needed to cover the dynamic social demands made by the use and choice of AT devices. Only the ICF is capable of embracing the complexities of care circle co-usage of AT for young children with severe motor impairments. However, the ICF currently has no associated design approaches that can support this breadth of coverage, in contrast to the i-cube, HAAT and CREATE approaches.

VI. SOCIO-DIGITAL AT

The ICF's 'biopsychosocial' neologism requires approaches to the design, selection and use of AT that can embrace the biological, personal, sociological and environmental factors that combine to determine an individual's capability. While the *biomedical* approach refers to the application of biological, medical, and physical sciences, once social and environment factors are also considered, the approach becomes *biopsychosocial*. Despite choice and use of computer-based AT being a sociodigital problem, most assessment and design models still take a predominantly biomedical approach. Those that do not still lack the breadth of the ICF. It is particularly important to go beyond simple biomedical approaches with young children where influence from personal factors such as past experience, upbringing, demographics and attitudes are still at a developmental stage and can be changed. Although it is not clear what specific design implications the ICF's biopsychosocial approach has for design, selection, and use, it nevertheless presents a Human-Computer Interaction (HCI) problem that needs to be urgently solved to enable support across the complex web of a physically impaired child's care circle, rather than just rehabilitation engineering augmentations of a child's body.

A. Socio-Technical Approaches

Within Information Systems and Interaction Design, there are well established *socio-technical approaches* to design and use that can embrace the interaction between humans, human activity, spaces, artefacts, tools and communication media [15]. The socio-technical philosophy holds that systems should never be designed or introduced without considering the softer issues such as the organisation or context of usage of the technical system. However, sociotechnical approaches historically have focused on single well defined technologies within a single organisational setting. While this was adequate for the digital technologies of the 1960s to 1990s, it is less able to cope with the wide range of personal and social factors (including multiple institutional agendas) of members of care circle choosing and co-using AT for communicating with young children. Furthermore, since the 1990s, media convergence has brought together multiple technologies and devices, combining their advantages.

B. The Impact of Convergence

Ubiquitous or pervasive computing is brought about by the convergence of media and environment, making interactivity more natural and seamless. Touch and gestural interfaces such as Apple's iPod

and iPhone, Microsoft Surface and Nintendo's Wii incorporate a variety of input, output, data, connectivity and interoperability. Interfaces that use natural and consistent input methods such as Microsoft Surface, with its multitouch interface, offer considerable promise for co-use of new ATs for communication. Most devices are now mobile: laptops, desktops and PDAs with both Windows and Mac operating Systems have similar interfaces, ergonomic design together with similar input, output and navigation. Able-bodied users are able to adapt to each of these different devices comfortably due to the many similarities. However impaired users, especially our target audience, in addition to overcoming their disabilities also have to adjust to different inputs, ergonomic designs and environment designs each time they use a different AT to communicate.

C. Socio-Digital Approaches

The original sociotechnical approach of considering a *single* social system alongside a *single* technical system does not appear to scale well to the complexities of care circles and digital convergence. While in principle, sociotechnical approaches need not be restricted to such simple structures, we prefer to use the more recent term *socio-digital* to refer to the complex web of social interactions via technology.

The scope of this more recent term is illustrated by the a research group that has adopted it as its name: "The Socio-Digital Systems (SDS) is an interdisciplinary group bringing together psychology, sociology, computer science and hardware engineering to address the problem of designing technology to support people in everyday life" [16]. SDS attempts to go beyond addressing technological problems and deals with designing for both the physical and social worlds. The most important element in a socio-digital system is even when technology is developed to counter a given objective; it must always get enmeshed in a social setting. The digital element is considered useless without the environment or its users. The socio-digital approach supersedes the socio-technical approach by looking at the interaction of AT across multiple social settings of families, informal groups and organisations.

To respond in full to the vision of the ICF, we thus need to develop socio-digital approaches to design, selection and use of AT. Interaction Design offers a wide range of possible approaches. For example, *Value Sensitive Design* refers to the design of technology being sensitive to ethical values throughout the design process [17]. This approach includes moral values, norms and moral considerations of the stakeholders as part of technological design, research and development.

D. Worth-Centred Approaches

Value(s) alone however are not strong predictors of a successful innovation and we also need to consider costs and benefits, as in *worth-centred* approaches. Worth is defined as sufficient value that warrants costs wherein which the design delivers sufficient value that outweighs costs of ownership and usage to the beneficiaries [19]. Worth for socio-digital AT selection and usage could be identified by identifying what people consider to be great communication experiences and achievements with young children with physical impairments as they develop. Costs and benefits could be identified by exploring care circle members' needs, wants, likes, dislikes and technical capabilities. These can be associated with AT features and capabilities via *Worth Maps*, network diagrams that identify means-end chains [19]. For AT to be worthwhile, the positive means-end chains through a worth map should outweigh the negative ones. Hence designing AT within the ICF biopsychosocial approach could be reformulated as *designing worthwhile socio-digital systems*. In doing so, we can draw on leading edge approaches to Interaction Design, including ones outlined by the Microsoft SDS research group in collaboration with leading HCI researchers [16].

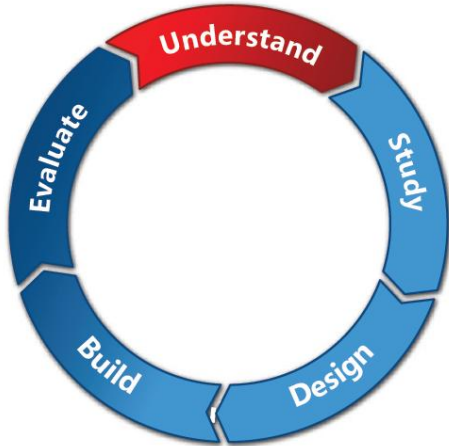


Figure 4 - User Centred Design Model^[19]

Microsoft's HCI 2020 proposes a development cycle for Socio-digital Interaction Design [18] that focuses on values and can be easily extended to focus on worth as a balance of costs and benefits (value/s) [20]. The 5 steps of the cycle (Figure 4) are:

1. *Understand*: Focusing on human values for research, consisting of reflective thought and conceptual analysis;
2. *Study*: Developing deeper understanding of the values identified in the first step;
3. *Design*: Reflect on the design goals and relate them to social settings;
4. *Build*: Low tech or high tech models are built;

5. *Evaluate*: Evaluate models built in step 4.

Methodologies based on this development cycle can focus on value, values and worth at an early stage of design, extending AT choice, use and new AT design interventions into the ICF-compatible space of worthwhile socio-digital systems. The first author is currently developing a research framework under the direction of the second author that will combine worth maps and related socio-digital approaches to AT.

VII. CONCLUSIONS

In a typical day in the life of a child with motor impairment, the child encounters various situations and various communication needs that arise from tasks that need to be carried out. The choice and use of AT devices that help them to carry out these tasks are chosen by numerous methods by various organisations. Some focus wholly or mostly on medical diagnoses and physical limitations sufficient to choose these devices, while others seek to choose and use individual AT devices in ways that meet needs across a range of social settings.

If the decision and investment made in the choice of AT device is to be worthwhile, decisions needs to be sensitive to the values and affordable 'costs' of members of a care circle. The valuable benefits that arise from meeting the 'ends' of their needs should outweigh the costs of the 'means' of choosing and using AT devices. If so, the result is a worthwhile socio-digital system centred on supporting the growth and development of a child who faces major challenges on a daily basis.

An apparent advantage of biomedical approaches is that they are objective, well-defined and closed, which makes them well suited to official agencies in discharge of their legal obligations towards children with special needs. However, neither the child, and still less their body, are a broad enough focus for AT design, choice and use. The ICF requires us to look beyond bodies to the complex social and physical environments within which people with impairments live their daily lives. Fortunately, emerging socio-digital approaches in HCI and Interaction Design have much promise for closing the gap between the aspirations of the ICF and the realities of current care circles and their support for developing children with severe motor impairment.

The ICF thus sets challenges that have yet to be fully embraced within accessibility research and the design of AT. However, meeting these challenges should be made possible through emerging approaches within Interaction Design and HCI that go beyond the simple sociotechnical consideration of the interactions between social and technical systems, to the

processing of worth within complex interdependent sociodigital systems. As a result, design needs to not only concentrate on assistive devices, but also on the use of communication and social networking technologies that can better support care circles in their collaborations to develop the abilities and interests of young children with extensive motor impairments. A research programme to meet the challenges of the ICF in this way is currently being refined. The aim is to maximise the benefits of assistive technology through collaborative selection and use of AT devices for and with children, while minimising the cost of this support and avoiding the adverse consequences associated with poor selection and usage difficulties with AT devices.

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A Social Approach to Accessible Social Networking using the CAT model

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Abstract. The social model of disability looks beyond medical and technical solution moving towards social approach. This paper applies the label and table attributes of the CAT models to understand the social setting of the child with the disability together with the care circle. It goes on to understand their social needs and identifies accessibility challenges in communication between members of the care circle. Evaluation is carried out in both a computer and Internet based environment and a traditional communication environment. Finally brief guidelines are drawn upon which an accessible social network based design solution could be built for the reduction of disability of children with motor impairment.

Keywords. Social model, CAT Model, Accessibility, Social Networking, Social Inclusion.

1 Introduction

The demand for social inclusion in services provided to the general public continues to grow. This not only applies to public places involving physical components, but also to virtual and online environments. This has been further emphasised by the amendment to Disability policies and legislation across the world in order to remove discrimination against disabled individuals.

1.1 Social Models of Disability

The Union of the Physically Impaired Against Segregation [1] developed the first social model that was modified by the Disabled Peoples International (DPI) [2]. This model defines the concept of impairment as “the functional limitation caused by physical, sensory, or mental impairments” and disability as “the loss or reduction of opportunities to take part in the normal life of the community on an equal level with others due to physical, environmental, or social barriers” [3]. Thus disability is not wholly a consequence of an individual’s functional limitations, but is also due to the

extent to which social environments limit the ability of impaired individuals to participate in everyday activities.

1.2 Rationale for social models

Increased opportunities will follow from bridging the gap through Assistive Technology (AT) and their associated human support systems. This requires communication “between the disabled end-user community, social services, the clinical rehabilitation services, and the professional engineering disciplines involved in the development, provision, assessment, and ongoing support for assistive technology” [3].

2 The CAT Model

Hersch and Johnson [3] have reviewed a range of models for accessibility: the HAAT model [4], MPT model [5], and the ICF [6] disability model. They concluded that their approaches to disability have remained predominantly medical, even when they have attempted to involve personal and environmental factors. Although the ICF defines disability as a condition defined by the environment and personal factors, the emphasis remains on the individual’s health and physical condition. In order to support the need, the Comprehensive Assistive Technology (CAT) has been developed to rebalance the medical and social. The CAT model’s top level of its hierarchy comprises of: Person Context, Activities and Assistive Technology (Fig.1).

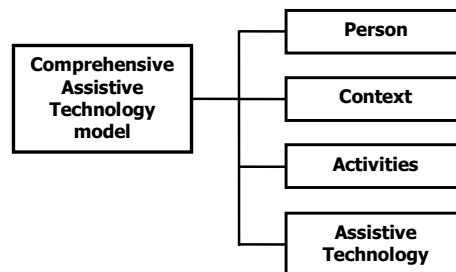


Fig. 1. CAT Model level 1

Social components from the three reviewed models have influenced the CAT model [3], offering a range of benefits, including:

- Identifying gaps in provision of assistive technology and develop systems where to meet need;
- Analysing existing systems to modify in order to improve existing devices;
- Developing design specifications for new devices;
- Providing support for design for all, providing a structure for design approaches.

The CAT model is represented using Tree diagrams, which provide visual support for design discussions; Labelled attributes support compact and tabular representations that can be commented. Alternatively, the CAT model can provide an initial specification of a model for specific case study, or can function as a checklist. Hersch and Johnson [7] have applied their CAT model within four independent case studies, involving real world usage environments and social settings. The first study demonstrated how CAT 'Person' and 'Context' attributes could be used to identify the target audience and the 'Activities' attribute could be used to identify accessibility challenges. The second study illustrated how a specific assistive device could be analysed using the CAT model. The third study showed how a potential communication solution could be designed by analysing the disabled individual. The fourth supported evaluation and choice of assistive technology for a specific individual. Further, the authors are conducting research that focuses on providing design support for a chosen user group.

This paper reports how the CAT model has been used to identify accessibility challenges and a potential solution within a research programme focused on the use of social networking. The aim is to support improved selection and use of assistive technologies for individuals with severe motor impairment, with a particular focus on young children, their families, and their wider *care circles* spanning neighbours, relatives, and community and professional groups.

This research is applying the CAT model within a wider framework of worth-centred design and evaluation approaches [8] to the development of a virtual social environment where the *care circle* for a disabled individual can co-ordinate and support everyday tasks. The aim of the research is to ascertain whether such a social network would actually reduce existing barriers to effective AT selection and usage, without creating new ones, e.g., through increased complexity.

2.1 Accessibility of Social Networks

Social networking web sites currently exclude many impaired users from social activities. AbilityNet [9] evaluated five social networking sites on accessibility and have described the challenges faced by disabled users and go on to suggest how they could technically be resolved. Unfortunately in the event where the user is unable to register on the social network, there is no analysis beyond that. The report focused on users' disabilities and technical features of the social network. The evaluation is particularly interesting as the subject of study is social in nature and covers every type of activity in the CAT model. This has been followed up by a further study by AbilityNet [10] concentrating on four key factors, which are seen by users as preventing users from engaging with social networks: Time on and complexity of tasks; Abrupt or regular interface changes; Text-based help "It would be nice to have videos or photos... text is hard to read sometimes"; A reduction in "perceived communication independence and privacy".

The CAT model is being applied to identify barriers that arise from common features of social networks for a defined set of activities. Analysis will be carried out separately for each user group and then combined to guide a design solution.

The research explores the limitations of accessibility based on technical and physical solutions and investigates how virtual environments could be made more accessible and effective by considering social and environmental factors. The aim is to use the CAT model to identify current barriers to activities, and to explore how social networks can be designed to overcome these barriers by enabling an impaired individual's care circle, rather than by simply modifying existing ATs. There is a specific focus on care circles of young children with cerebral palsy, but the developed social network support will generalise beyond this group.

2.2 Identifying accessibility barriers of Care Circles

With a view to understanding the barriers those members of the care circle face in real life, the CAT model level 1 is applied to the functionality and needs of care circle. This step follows the first case study of Hersch and Johnson [7] where the person and context components of the model have been defined using the labelled attribute representation to provide information about the end-user group and their context.

Our primary focus is the child with motor impairment. A child's capability and needs are assessed by medical practitioners and assessment centers with support from family members, school teachers, teaching assistants, speech and occupational therapists whenever possible. This could be for the initial assessment to choose suitable assistive devices or regular challenges they face as the child learns new skills and works towards being independent. The Person and Context sections of the CAT model attempts to understand the functionality and the needs of the child and the care circle.

Person (P): *P.1 Characteristics:* *P.1.1 Personal information:* Children up to the age of initial tertiary education, both genders, diverse fitness, lifestyle and educational needs; *P.1.2 Impairment:* Could have sensory, or motor impairment; Motor impairment here means that, with support, the person is able communicate. ; *P.1.3 Skills:* Basic motor skills, though coordination is reduced, able to follow instructions given verbally, or using audio-visually; *P.1.4 Preferences:* communicate with all involved in their regular decision-making, active life, doing things themselves with technology if necessary, but without personal assistance.

P.2 Social aspects: *P.2.1 Community support:* Most children have support from family members, medical and educational practitioners. Some also have support from friends and/or local community/organisations; *P.2.2 Education and employment:* Actively involved in either vocational or academic education

P.3 Attitudes: *P.3.1 Attitudes to assistive technology:* Willing to use assistive technology as long as it is fun, entertaining and helps them communicate with care circle members and provides them with more independence. Slightly older children are also concerned with its appearance; *P.3.2 General attitudes:* independence is important, but compared to older individuals children seek gradual independence.

Context (C): *C.1 Cultural and social context:* *C.1.1 Wider social and cultural issues:* All children speak English with some who understand a second language but there are members of the care circle for example, grandparents who do not speak

English; *C.1.2 User's social and cultural context*: Diverse multicultural society but adapt to local cultures.

C.2 National context: *C.2.1 Infrastructure*: Modern infrastructure, newer technologies, Assistive Technology is used and computer and internet access is available to most; *C.2.2 Legislation*: Disability discrimination legislation and accessible web content guidance in place with increasing enforcement; *C.2.3 Assistive technology context*: A wide range of assistive technology is available and there is some financial and other support to obtain them. Facilities for repair and maintenance are also available. There are challenges in identifying and using the most appropriate device with most devices ending up in the cupboard unused.

C.3 Local settings: *C.3.1 Location and environment*: Classroom, school environment, home and other regular social settings; *C.3.2 Physical variables*: Moderate temperatures, sometimes noisy and/or crowded environments.

Table 1. Activities (plain text indicates no accessibility barrier, *italic* indicates *mild* barriers; **bold italic** indicates *moderate* barriers, and **bold** indicates *severe* barriers)

Accessibility barriers for care circle members for communication			
Activities: Mobility Impaired Group	Category of Activity	Accessibility status for communication of care circle	
		Without internet	With internet
	Communication and Access to information	All information only locally available	Information locally and remotely available
		Access to information locally available or personal copies	Access to digital copies available on demand
		<i>Telecommunications</i>	Email, chats, forum, groups
		<i>Low tech devices</i>	<i>High tech devices</i>
		<i>Observations, visual, audio, text</i>	Observations, visual, audio, text
		Travel time and cost	Minimum travel time and cost
	Mobil-ity	<i>Travel to meetings</i>	Access needed to internet
		<i>Fine motor skills i.e. writing</i>	<i>Accessible input/output</i>
		Synchronous discussion	Synchronous and asynchronous discussion
	Cognitive activities	Analysing, assessing and evaluating information	Analysing, assessing and evaluating information
		<i>Logical, creative and imaginative thinking</i>	Logical, creative and imaginative thinking
		<i>Planning and organising</i>	Planning and organising
		<i>Decision making</i>	Decision making
		<i>Categorising</i>	Categorising
		<i>Calculating</i>	Calculating
		<i>Experiencing and expressing emotions</i>	Experiencing and expressing emotions

Activities: Mobility Impaired Group	Daily living	Personal care and hygiene	<i>Personal care and hygiene</i>
		One-one support	Peer and expert support
		<i>Environmental control</i>	Virtual environmental control
	Education and employment	Learning and teaching	e-learning and teaching
		Individual and group based activities	Emails, chats, forums and conferences
		Curriculum and therapy	Curriculum and <i>therapy</i>
		Indoor and outdoor activities	Social gaming activities
		<i>Extra curricular activities</i>	Extra curricular activities
		Occupational therapy	<i>Occupational therapy</i>
	Recreational activities	Home, school and other clubs	Different online groups
		Individual and team based	Online gaming
		Holidays and visits: museums, galleries, heritage sites	Web browsing
		Indoor and outdoor sports	<i>Indoor and outdoor sports</i>
		Art and handcrafts	<i>Art and handcrafts</i>
		Social events	Online social events

Table 1 shows the outcome of the checklist approach to identify potential barriers to communication between care circle members both with and without the use of the computers and Internet, indicating potential reductions in accessibility barriers.

It shows the accessibility challenges of children with motor impairment and their care circle members. Taking into consideration that a virtual or online solution is suggested, the potential impact is shown in the right column, with some details of potential web-based solutions. However there are residual challenges that could only be met with further assistive devices.

2.3 Improving Accessibility of and Through Social Networking Web Sites

The third case study of Hersch and Johnson [7] is being applied to identify a potential design solution to meet the needs of the care circle.

Activity (A) - Assessment for choice of appropriate assistive devices

Assistive Technology - AT

AT.1 Activity specification - AT.1.1 Task specification:

Involvement of all possible members of care circle, who would potentially be communicating with the child using the assistive device; **AT.1.2 User requirements** Convenient and user friendly interface with access to a single platform; entire care circle should be able to participate at the discretion of the parent or official guardian of the child; should not demand additional time or cost in travel; should be able to obtain continuous support from the distributor and decision maker.

AT.2 Design issues - AT.2.1 Design approach: Design for the child and members of the care circle an accessible interface where they could log in, discuss and make decisions securely. The interface should be inclusive of many types of disability on web-based interfaces.

Architecture: Web-based social network where a few people have the rights to approve members of the care circle to be involved with the child. This network could be accessed remotely either by a personal computer or a mobile phone-based device. *Device realisation:* the child's profile, calendar with events, chats, videos, technical support for the assistive devices, and any other up-to-date discussions could be shared according to the privileges assigned by the parent or guardian. *Options:* The interface should be compatible with still images, audio, video and text information.

AT.2.2 Technology selection

Input: The user should be able to access and interact with the information by keyboard, mouse, touch, stylus or any other assistive device that the would otherwise use to interact with the personal computer or smart phone.

Output: The display should be compatible with most computer resolutions and mobile phones; if necessary, individual applications should be made for mobile phones.

Programming: Could use any language that does not work against web accessibility guidelines [11].

AT.3 System technology issues

AT.3.1 System interfaces

Standard accessible web components should be used to reduce the need for specialized plug-ins.

AT.3.2 Technical performance

The system needs to be secure as sensitive information relating to a person under the age of eighteen would be included; there will also be an application of Data Protection and Privacy related legislation due the nature of information concerned.

AT.4 End-user issues

AT.4.1 Ease and attractiveness of use

The system needs to be informative, robust, usable and provide options in choice of variety of themes to include users with visual impairments; design themes for personal preference could also be provided;

AT.4.2 Mode of use

Whenever possible there should be an option of online and off-line modes.

AT.4.3 Training requirements

Information should be arranged with the best possible information architecture to reduce training; suitable help should be provided.

AT.4.4 Documentation

There should be an archive feature for all information and an option to print any information for those who may require a hard copy; this option should be bound by a data protection agreement.

The above has illustrated how the CAT model can be used by researchers other than its authors to structure the initial user research and design for a social network that could reduce the challenges facing care circles, thereby enhancing the capabilities of the child. This application of the CAT model will be continuously iterated and continuously evaluated as the system is being developed. It will thus extend into a more comprehensive design specification.

3 Conclusion

The CAT model (and the WHO ICF on which it is based) relates activity limitations to personal and environmental factors that cannot be overcome solely through the design of assistive technologies. Instead, it is the understanding and use of assistive technologies by and with care circles that can make impacts that technology alone cannot. This research applies the CAT model to identifying challenges for care circles and thereafter identifying potential design solutions to meet the needs of the identified challenges. A social network has been chosen to improve the capabilities of care circles to support and improve the selection and use of assistive technologies by individuals with physical and/or mental impairments.

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